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**Living with acute coronary syndrome  
and prediabetes:  
An interpretive description  
of complex illness**

A thesis presented in partial fulfilment of the requirements for the degree of

Doctor of Philosophy

in

Nursing

at Massey University

Wellington, New Zealand.

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2013

## **Abstract**

The purpose of this research is to reveal the experience and interpretation people have of cardiovascular disease (CVD) and prediabetes as complex illness. CVD and diabetes are both increasing in prevalence in New Zealand and globally. Prediabetes is known to be precursory to type 2 diabetes; CVD and prediabetes are fast becoming an established comorbidity. As the prevalence of complex illness soars, the experience and interpretation people have of their condition requires deeper appreciation by nurses as members of a practice discipline.

This doctoral research draws attention to the experiences as interpreted by participants and subsequently by the researcher, using interpretive description informed by Gadamer and Merleau-Ponty. Thirty three participants with CVD and prediabetes were recruited into this study. Open ended interviews were undertaken in hospital before discharge and then approximately 9 months later in the community. Interviews were transcribed, data managed by NVivo 9 software, data analysed using thematic analysis, and a thematic framework was developed to organise themes. The overarching theme is in/conspicuous detail indicating the visible and the invisible elements of complex illness. The two major themes, invisible disequilibrium and dialogue as caring, foreground further subthemes and embedded subthemes. The major theme invisible disequilibrium describes the experience of illness and is supported by three subthemes: losing equilibrium, becoming embattled and making sense of evolving illness. The second major theme dialogue as caring interprets the experiences participants had and is supported by subthemes: restorative dialogue, caring and constructing illness.

Major findings indicate that complex illness is heterogeneous and participants were continually working with and making sense of the conspicuous and less conspicuous detail of 'the whole'. Further findings include the proclivity of risk (choice) as a function of participants' lifestyle such as diet type, activity levels, understanding of medications, plus how this risk may in the longer term cause disease and illness. A third major finding is that participants focussed on self-care as part of their construction of illness.

This research provided insights into the experiences of people with CVD and prediabetes. It also showed that complex illness is the occurrence of an intricate meshing of personal circumstances, signs and symptoms that requires attending to needs as identified by the patient. This continues the debate concerning how illness affects the lives of individuals, potentially influencing future service planning.

## **Acknowledgements**

An enormous debt is owed to all the participants in this research who played an essential role in coming to understand more about the experience of complex illness. It is the inconspicuous details of their lives that constantly motivates many health professionals and researchers to come to know this enigma further.

My supervisors both past and present have been important in maintaining momentum in the completion of my work. In the last year of my writing I was privileged to work with a remarkable group of supervisors: a biochemist, a geneticist and a social scientist. I applaud all three of you, because of your insight and ability to extend me beyond the safety of 'my patch'. Special thanks are due to Associate Professor Rachel Page, my principal supervisor, who stood by me during the entire project. Rachel you have my deepest respect for your unstinting belief in this project, expert scholarly contribution and indefatigable passion for excellent research. Many thanks are also extended to Dr Michelle Thunders as co-supervisor for your erudite intellectual and editorial contribution. Finally my thanks are to Dr Karen McBride-Henry as co-supervisor for your unrivalled clarity in working within the domain of applied qualitative research, and courage to 'be there' when your life was already so full.

I would like to acknowledge financial support for this research from the Massey University Scholarships Committee (2008-2011). Added to this I received funding from the Institute of Food Nutrition and Human Health Postgraduate Research Support Fund (2010) and the School of Health and Social Services Graduate Research Fund (2011) for transcription of interviews.

Another group of people to thank is the research group that I worked with closely in the clinical setting. Thanks are extended to Dr Jeremy Krebs, Lindsay McTavish, Berni Mara, Dr Scott Harding. Special thanks are extended to Margaret Ward RN.

## Dedications

This thesis is dedicated to my much loved family:

First to my Pap and Mam, both who had enormous positive influence on my life and always will. Mam's maxim I can hear now:

“Wees een flinke knappe meid, die in bange uren stevig door de apple bijt, ook al is't een zure!”

To Bizzy Girl, always the light on dark days, as there were a few during this journey (and yes we can now finally go to shopping).

And to dear Blake (aka SH the rock), what support and (endless) humour you have offered and thanks for all the coffee; do svidaniya Boris.

## Table of Contents

Abstract.....	i
Acknowledgements.....	ii
Dedications .....	iii
Table of Contents.....	iv
Appendices.....	x
List of Tables .....	xi
Chapter 1 .....	1
Introduction to doctoral study .....	1
1.1 Introduction .....	1
1.1.1 Working as a nurse.....	2
1.1.2 Working as a researcher .....	2
1.1.3 Working as a nurse researcher.....	3
1.2 Research questions and aims .....	5
1.3 Background .....	5
1.3.1 Cardiovascular disease and diabetes .....	6
1.3.2 Prediabetes and insulin resistance.....	7
1.3.3 Screening and managing risk factors: CVD and prediabetes.....	11
1.4 Nursing practice and research: CVD & prediabetes .....	12
1.5 HRC/DHB funded translational research: Reduce Incidence in Cardiovascular Events (RICE) study .....	13
1.6 Overview of this thesis.....	17
Chapter 2.....	18
Literature review: Constructing illness.....	18
2.1 Introduction .....	18
2.2 Search strategy for literature review.....	18
2.3 Defining illness .....	19
2.3.1 Definition of illness for this doctoral research .....	21
2.4 The experience of illness .....	21
2.4.1 Historical readings: The experience of illness .....	21
2.4.1.1 Illness as metaphor .....	22
2.4.1.2 Illness as a human condition .....	22

2.4.1.3 Other important sources of research .....	22
2.4.2 Contemporary nursing research: Experience of illness .....	23
2.4.3 Concepts foundational to the experience of illness .....	26
2.5 The experience of illness as singular diagnosis .....	28
2.5.1 The experience of cardiovascular disease .....	29
2.5.2 The experience of type 2 diabetes .....	30
2.5.3 The experience of prediabetes.....	32
2.6 The experience of living with a new diagnosis.....	33
2.7 The experience of comorbidity as complex illness.....	33
2.8 The interpretation of illness: Patients' perspectives .....	36
2.8.1 Interpretation: A definition.....	36
2.8.2 Many interpretations of interpretation: The patients' perspectives .....	37
2.9 The experience and interpretation of illness .....	38
2.10 Framing up the research.....	39
Chapter 3 .....	40
Theoretical perspective of research .....	40
3.1 Introduction .....	40
3.2 Theoretical perspective influencing the research.....	41
3.3 Interpretivism.....	41
3.3.1 Gadamer .....	42
3.3.1.1 Bildung.....	42
3.3.1.2 Prejudice .....	43
3.3.1.3 The Whole.....	43
3.3.1.4 Understanding and Interpretation .....	44
3.3.1.5 Fusion of horizons.....	45
3.3.2 Merleau-Ponty .....	45
3.3.3 The influence of interpretivism on research method .....	46
3.3.4 Interpretivism as central to understanding illness .....	48
3.4 Interpretivist Ontology and Constructivist Epistemology.....	49
3.5 Constructivism.....	50
3.5.1 Construction of patient knowledge .....	51
3.5.2 Discrimination of knowledge constructed by patients .....	51
3.5.3 Patient knowledge: Central to nursing knowledge .....	52
3.6 Qualitative health research.....	53
3.6.1 Peculiarities of being a qualitative researcher in clinical settings.....	53
3.7 Conclusion.....	55

Chapter 4.....	56
Research methodology: Interpretive description.....	56
4.1 Introduction.....	56
4.2 Origins: interpretive description.....	56
4.3 Synergy: Theoretical perspective with interpretive description.....	57
4.3.1 Constant interpretation.....	58
4.3.2 Co-construction as method or ontology?.....	58
4.3.3 Meaning making in interpretive description.....	59
4.3.3.1 Understanding.....	59
4.3.3.2 Understanding with prejudice.....	60
4.3.3.3 Description.....	60
4.3.3.4 Inductive analysis.....	61
4.3.3.5 Applied nature of interpretive description.....	61
4.4 Interviewing for interpretive description.....	62
4.4.1 The interview.....	62
4.4.2 The interviewer.....	63
4.5 Evaluation criteria for an interpretive description.....	64
4.5.1 Epistemological integrity.....	65
4.5.2 Representative credibility.....	65
4.5.3 Analytic logic.....	66
4.5.4 Interpretive authority.....	66
4.6 Conclusion.....	67
Chapter 5.....	68
Methods.....	68
5.1 Introduction.....	68
5.2 The researcher's expertise.....	68
5.3 Participants.....	69
5.4 Ethical considerations.....	69
5.4.1 Insider and outsider considerations.....	69
5.4.2 Informed consent and confidentiality.....	70
5.4.3 Privacy.....	70
5.5 Collection of data.....	71
5.5.1 Interview process.....	71
5.5.1.1 Interview 1.....	72
5.5.1.2 Interview 2.....	72
5.5.1.3 Management of interview data.....	73

5.5.1.4 Management of interview data using software .....	74
5.5.2 Reflective account .....	74
5.6 Analysis of interview data .....	75
5.6.1 Preparation for analysis .....	78
5.6.2 Preliminary thematic analysis.....	78
5.6.3 Ongoing iterative analysis .....	79
5.6.3.1 Analysis using NVivo 9 software.....	80
5.6.3.2 Coding.....	80
5.6.3.3 Theme development.....	81
5.7 Emergent interpretation.....	81
5.7.1 Verification of interpretation with supervisors.....	82
5.8 Conclusion.....	82
Chapter 6 .....	83
Descriptive findings: thematic framework .....	83
6.1 Introduction .....	83
6.2 Thematic framework.....	83
6.3 In/conspicuous detail.....	88
6.4 Invisible disequilibrium .....	90
6.4.1 Losing equilibrium .....	90
6.4.2 Becoming embattled .....	91
6.4.3 Evolving illness.....	95
6.5 Dialogue as caring .....	96
6.5.1 Restorative dialogue.....	97
6.5.2 Caring.....	98
6.5.3 (Re)constructing illness .....	99
6.6 Conclusion.....	101
Chapter 7 .....	102
Interpretive findings: Invisible disequilibrium .....	102
7.1 Introduction .....	102
7.2 Invisible disequilibrium .....	103
7.2.1 Losing equilibrium .....	103
7.2.2 Becoming embattled .....	107
7.2.2.1 Humour alleviating embattlement.....	109
7.2.2.2 Contemplating surgery .....	111
7.2.2.3 Delaying seeking advice .....	112
7.2.3 Evolving illness.....	113

7.2.3.1 Perceptions of social constructions.....	115
7.2.3.2 Reliving a disarray of events.....	117
7.2.3.3 Experience of the living body.....	119
7.2.3.4 Awareness of pain and the living body.....	122
7.2.3.5 Illness evolves by remaking life.....	123
7.3 Conclusion.....	124
Chapter 8.....	126
Interpretive findings: Dialogue as caring.....	126
8.1 Introduction.....	126
8.2 Dialogue as caring.....	127
8.2.1 Restorative dialogue.....	129
8.2.1.1 Dialogue for sharing burden.....	131
8.2.1.2 Medicalisation of detail.....	133
8.2.2 Caring.....	136
8.2.2.1 Life routines.....	137
8.2.2.2 Conspicuous medications.....	141
8.2.2.3 Conspicuous risk.....	144
8.2.2.4 Information.....	146
8.2.2.5 Caring for self.....	148
8.2.3 (Re)constructing illness.....	150
8.2.3.1 New constructions of illness.....	150
8.2.3.2 Perceiving well-being.....	152
8.2.3.3 Constructing complex illness.....	153
8.3 Conclusion.....	158
Chapter 9.....	159
Discussion.....	159
9.1 Introduction.....	159
9.2 Reflection upon interpretive reflection.....	159
9.3 Outline of findings.....	161
9.4 Summary of findings.....	162
9.5 Risk in the construction of illness.....	165
9.6 Self-care in the construction of illness.....	168
9.7 Complex illness as experience of ‘the whole’.....	170
9.8 Implications for nurses working with people with complex illness.....	172
9.8.1 Recommendations for nursing practice and research.....	172
9.9 Other possible themes and concepts relevant to this research.....	174

9.10 Limitations of the research .....	177
9.10 Conclusion .....	178
Chapter 10 .....	180
Conclusion.....	180
10.1 Introduction.....	180
10.2 Returning to the research.....	180
10.3 Future research .....	182
10.4 Final conclusion.....	183
References .....	184

## Appendices

Appendix 1 Criteria for diabetes and prediabetes, New Zealand Society for the Study of Diabetes, September 2011.....	210
Appendix 2 Health and Disability Ethics Committee, Central Regional Ethics Committee, ethics approval letter, August 2009.....	211
Appendix 3 Letter of invitation for prospective participants.....	213
Appendix 4 Information sheet for participants.....	215
Appendix 5 Consent form for participants .....	221
Appendix 6 Table: Participants interviewed as per timing and location for interview 1....	222
Appendix 7 Interview schedule for interview 1 .....	223
Appendix 8 Selected additional questions for prompting participants .....	225
Appendix 9 Interview schedule for interview 2 .....	226
Appendix 10 Confidentiality agreement for transcribers .....	229
Appendix 11 Covering letter for interview (1 and 2) transcript verification by participants.....	230

## List of Tables

Table 1.1 Summary of recent New Zealand prevalence data for cardiovascular disease and diabetes.....	7
Table 1.2 Longitudinal and/or comparative studies: prevalence for impaired glucose metabolism and cardiovascular disease.....	10
Table 1.3 Baseline characteristics for RICE study participants.....	15
Table 1.4 Clinical parameters on admission and nine months after discharge for RICE study cohort.....	16
Table 1.5 Table 1.5 Socio-demographic description of participant group for doctoral study .....	17
Table 2.1 Examples of nursing research exploring the experience of illness.....	24
Table 2.2 Table of summarised qualitative nursing research: the experience of illness.....	26
Table 2.3 The experience of living with co-morbidity: nursing and non-nursing literature...35	
Table 5.1 Appearance, Environment, Emotion, Cognition (AEEC) Tabulation: interview 1, participant 2, no prediabetes.....	76
Table 5.2 Appearance, Environment, Emotion, Cognition (AEEC) Tabulation: Interview 2, participant 13, diabetes diagnosed by general practitioner.....	77
Table 6.1 Thematic framework representing participants experience and interpretation of complex illness .....	84
Table 6.2 Comprehensive thematic framework (extended framework Table 6.1) .....	86-87
Table 9.1 Thorne’s evaluation criteria .....	161
Table 9.2 Summary extending thematic framework (Table 6.1) with additional embedded themes .....	162

# Chapter 1

## Introduction to doctoral study

### 1.1 Introduction

There is worldwide urgency to curtail the escalation of cardiovascular disease and diabetes because of the resulting economic, social and personal burden (Gakidou et al., 2011; World Health Organization, 2008). The research presented in this thesis explores the experience people have of cardiovascular disease (CVD) and prediabetes, and how they come to interpret these experiences. In part this research intends to clarify how patients interpret risk factors and comorbidity. In clinical settings it is noticeable that patients present with increasing comorbidity (Williams & Botti, 2002). Therefore a further aim of this research was to consider clinical opportunities that nurses ought to be using to highlight risk that may affect patients prospectively. This may include nurses remaining astute to appropriate systems of health care management and referral for patients, particularly those that have significant illness.

The temporal focus of this doctoral project is on the experience of illness at two points in time: admission to hospital and once discharged home (approximately 9 months post-admission). The contextual focus is on those people admitted to hospital with an episode of acute coronary syndrome coupled with the unexpected discovery of high blood glucose. The intention was to synthesise the information that participants offered in their interviews at two points in time to distil the meaning of the participants' experiences and interpretation of their illness. To this end, I interpret the participants' interpretation as a reconstruction of them living with illness.

The chosen contextual circumstance for this research is significant because it begins to address the patient perspective of specific comorbidities; CVD and prediabetes (latterly known as impaired glucose metabolism). Blood glucose levels are rising in people living in both developed and developing countries (Tabák, Herder, Rathmann, Brunner, & Kivimäki, 2012). Hyperglycaemia and CVD are growing in prevalence both separately and as comorbidity. Added to this, the risk of CVD increases as hyperglycaemia increases within normoglycaemic limits (Bartnik, Norhammar, & Rydén, 2007; Grundy, 2012). Prediabetes is the term given to a continuum: those that manifest high blood glucose but not high enough to be diagnostic of diabetes mellitus, through to those with evident diabetes. People with sustained high blood glucose run substantial risk of developing type 2 diabetes

and further cardiovascular disease (Abdul-Ghani & DeFronzo, 2009; De Caterina, Madonna, Sourij, & Wascher, 2010; Tabák, et al., 2012). For this reason it is timely that research should focus on people that have both CVD and unidentified high blood glucose in order to learn from the patients' experience.

The experiences brought to this research are: the personal experience of supporting parents with significant illness, working for numerous years as a clinical nurse with people with comorbidities, and now teaching students of nursing who regularly inquire of the intricacy of illness beyond what textbooks offer. These factors all contribute to a resolve to explore illness as a response to various factors that interconnect: how patients experience and interpret their illness, and how risk factors and comorbidities are perceived in patient constructions of illness, and how this information contributes to nursing knowledge. This type of research is best suited to a philosophical perspective aligned to qualitative methodologies that embrace patients' perspectives in the clinical setting.

### **1.1.1 Working as a nurse**

Over a period of twenty eight years I gained valuable insights into how patients experience illness. Often working in acute medical settings, it was inspiring to note the resilience of people who were faced with composite medical and psychosocial circumstances. Accordingly, I view nursing as a science and an art: a scientific profession based on research, with a resolve to sustain the art of caring. A similar view is expressed in the current nursing literature, wherein nursing is no longer constrained by the traditions of function and skills; nursing involves working with intellect and conscience (Jasmine, 2009; Jonsdottir, Litchfield, & Pharris, 2004; Litchfield & Jónsdóttir, 2008; Parker, 2010).

Over the years it has become evident that science plays a central role in how I deliver nursing care, how I teach and now how this doctoral research is accomplished. This does not diminish my commitment to the art of nursing, the care of and caring about a person with illness. This doctoral research has a particular focus on the art of nursing i.e. how people experience illness, thus how people change because of the experience of illness. To this end, the research links how science has become a part of the participant's experience, indeed a part of their constructed knowledge about illness.

### **1.1.2 Working as a researcher**

When doctoral research is undertaken, there is an expectation that one will justify particular theoretical perspectives of the research in hand. All research is theory-driven, but particular care is taken to make this explicit by those researchers who adopt a qualitative perspective (Thorne 2008).

The theoretical position of this research is interpretivism and constructivism, which philosophically informs the methodology: interpretive description. In turn, interpretive description is an understanding of how to execute good research, which has been developed and reported by nurse scholars (Giddings, Roy, & Predeger, 2007; Oliver, 2011; Thorne, 2008). The intention of interpretive description is to conceive a methodological strategy that is specifically orientated to research in clinical settings and goes beyond a qualitative description. This methodology came to fruition during a time nurse researchers sought a qualitative approach for their work which was not theoretically aligned to traditional perspectives such as grounded theory, phenomenology or ethnography (Sandelowski, 1986). Consequently interpretive description provides clinical researchers with a logical structure to execute research and a cogent argument to position research in clinical settings, where a central aim is to make clear associations between research findings and nursing practice.

### **1.1.3 Working as a nurse researcher**

Research concerning the “patient experience” is burgeoning especially in the nursing literature (Wilkes, Cioffi, Warne, Harrison, & Vonu-Boriceanu, 2008). The focus of this research extends the exploration of “experience” to include the patient/participant’s interpretation of illness. Patients I have worked with over the years have varying levels of insight into their illness. It is the interpretation of their experiences, as their construction of understanding that I became interested in, and forms a basis of this doctoral research.

My background in research as a nurse began in 1990. During the 1990s I worked as a nurse managing clinical trials for new antihypertensive medication at the local medical school (Otago University, Wellington, New Zealand). In my work at the medical school there was little research focussing on the patient’s experience of illness. Therefore I undertook a Master of Nursing by thesis, highlighting the experience of covert symptoms, focussed on high blood pressure, the thesis entitled “High blood pressure as a way of life”. This research strengthened my resolve to continue clinical research, putting the patient experiences foremost to improve clinical practice.

In the 1990s the research teams I worked with focussed their work around risk factors and how this should apply to the health of communities and individuals alike. The phrase “risk factor(s)” is also a feature of this research; and for the purposes of this research is taken to mean a factor potentially causing or predisposing one to disease (Macha & McDonough, 2012). Well established risk factors are frequently related to lifestyle, exposure to specific environments genetic and/or ethnic background. Risk factors in various combinations can give rise to not one disease but potentially multiple pathophysiological phenomena. The issue of comorbidity helped crystallise my research

point of difference to question how people standing at the crossroad of comorbidity, experience and interpret risk factors during the course of their illness. Relating this specifically to the participants in my research I asked “How do people interpret the significance of high blood glucose in conjunction with cardiovascular disease?” Furthermore, there is the issue of risk factors posing a threat to public health and health service demand. The central issue is what O’Neill (2002) describes as public health or clinical ethics. The dilemma she presents is the importance of epidemiological observation (including risk factors) culminating in grouping people into broad categories of ill health, with particular public health policy assigned to patient cohorts. Contrary to this public health stance, there is constant demand to tailor health service provision to preserve individual autonomy and encourage independence. Goodyear-Smith (2010) rewords this predicament as population versus individual health, Macha and McDonough (2012) tells us that of necessity the two forms of health coexist.

The word ‘comorbidity’ though recruited from medicine is a recurring notion in this research. Williams writes that its meaning indicates the coexistence of two or more (un)related medical diagnoses, often chronic conditions (2010, p. 58). Comorbidity indicates: compound aetiology, diagnoses and multiple risk factors due to assorted disease states. The participants in this research had comorbidity as CVD (specifically acute coronary syndrome) and prediabetes, but their experience was much more than comorbidity. Their experience was of an intricate meshing of signs, symptoms and circumstances, which I denote as complex illness in this document. Where the word ‘comorbidity’ is used in this document, it has been chosen to reflect a medical sense. ‘Complex illness’ is more in keeping with the research question concerning experience, understanding and ultimately how people interpret their illness both in a practical sense and as an existential being.

To conclude, this research aims to explore how patients experience and construct an understanding of illness, and how risk factors and comorbidity are part of this constructed understanding of illness, if at all. The patients’ perspective of this intersect of concepts is not explicitly found in current literature, so research exploring these patients’ perspectives may illuminate further the art and science of nursing, particularly concerning complex illness.

The rest of this chapter identifies the research questions and aims (Section 1.2), introduces screening, an overview of cardiovascular disease, diabetes and prediabetes (Sections 1.3, 1.3.1, 1.3.2), risk factors (Section 1.3.3), introduces nursing research that has been undertaken concerning CVD and prediabetes (Section 1.4), introduces related research (the RICE study) which this doctoral research project is a part of (Section 1.5, 1.6), and finally provides a thesis overview briefly describing each chapter (Section 1.7).

## **1.2 Research questions and aims**

Only in the last decade has qualitative research included the multifaceted nature of illness as the experience of comorbidity (2004), or multiple chronic conditions (Clarke, Griffin, & The PACC Research Team, 2008). Therefore for this research it was significant to reveal how people experienced both an admission diagnosis (an acute coronary syndrome event) plus a new diagnosis (prediabetes); to explore what their experience was of complex illness.

Research literature (Morse & Johnson, 1991) appears to congregate chiefly around ‘experience’ as a primary focus. The research questions of this study were:

1. What is the experience of people who are admitted to hospital with an acute coronary syndrome event and then find they also have high blood glucose, and what is their interpretation of their complex illness?
2. What is the experience of people who are discharged from hospital back to the community after an acute coronary syndrome event and also have high blood glucose, and what is their interpretation of their complex illness?

The research questions are multifaceted and bring up the notion of temporality plus locate a focus upon how participants experience and then interpret living with complex illness. For this reason two further research aims arise from the two research questions, which are:

1. To describe and synthesise experiences people have around the time of hospitalisation and after discharge home, concerning acute coronary syndrome and high blood glucose,
2. To explore how people experience and interpret complex illness.

## **1.3 Background**

The experience of illness is well researched, with publications focussed on illness as a singular disease entity (Jónsdóttir, 2008; Morse & Johnson, 1991) or singular concept thereof (Lubkin & Larsen, 2009; Madjar & Walton, 1999). There is less research dedicated to the experience of illness identifying itself as a multiple disease state (Clarke, et al., 2008). The literature attending to the experience of multiple disease as illness can be found termed as: comorbidity (Whittemore & Dixon, 2008; Williams, 2004, 2010), multiple chronic conditions (Clarke & Bennett, 2012; Clarke, et al., 2008), secondary complications (Collins & Reynolds, 2008) or coexistent disease (Weiss & Hutchinson, 2000).

Comorbidity in nursing research stresses the need for nursing care to revolve around the needs of patients which can be multifaceted if patients have multiple diagnoses (Giddings & Roy, 2008). In research by Williams Dunning and Manias (2007), comorbidity was often not considered by nursing staff. As an example, patients with osteoarthritis in hospital for knee joint replacement were expected to have the same clinical pathway of recovery as a person without comorbidity. Ultimately comorbidities affected general well-being of patients and importantly delayed recovery from surgery, extending hospitalisation and recovery. These examples highlight complex illness rather than comorbidity. Multiple disease as illness or comorbidity is the coexistence of diseases that any one person may develop (Sarfati, Hill, Purdie, Dennett, & Blakely, 2010; Williams, 2004). It is not clear what the frequency is of comorbidity in New Zealand (Sarfati, et al., 2010).

Complex illness for this doctoral research relates to people with acute coronary syndrome (ACS) and prediabetes. An overview of the pathophysiological and epidemiological understanding of CVD and prediabetes are presented next, to situate the research.

### **1.3.1 Cardiovascular disease and diabetes**

Globally, coronary heart disease and diabetes mellitus both feature in the top ten leading causes of death projected for 2030. Coronary heart disease is ranked first making up 13.4% total deaths while diabetes is ranked seventh predicted to make up 3% of total deaths (Mathers & Loncar, 2006).

Type 2 diabetes increases the risk for cardiovascular disease (Bartnik, et al., 2007), two to four times (Laakso & Kuusisto, 2003).

The New Zealand picture is summarised in Table 1.1. The New Zealand Portrait of Health (Ministry of Health, 2008) reports that one in twenty (5%) adults have been diagnosed with coronary heart disease. The same prevalence was found for diabetes in New Zealand adults i.e. 5%. Of all these people with diabetes, type 2 diabetes was found in nine out of every ten people (90%). The Portrait of Health data does not provide information about prevalence for people who have a combination of these diagnoses. The Aotearoa New Zealand Health Tracker (ANZHT) study determined co-prevalence for gout, cardiovascular disease and diabetes for 2008/9 (Winnard et al., 2013). Winnard (2013) also found that for those people with gout, 22.7% had cardiovascular disease and 25% had diabetes.

**Table 1.1 Summary of recent New Zealand prevalence data for cardiovascular disease and diabetes**

Prevalence source	CVD only	Diabetes only
Portrait of Health (Ministry of Health, 2008)	5% of population (2006/07 data)	5% of population (2006/7 data)
Aotearoa New Zealand Health Tracker (Winnard, et al., 2013)	5.4% crude prevalence (2008/9 data)	6.6% crude prevalence (2008/9 data)

The prevalence of diabetes (type 1 and type 2) is 4.1 times greater for Pacific people and 2.8 times greater for Maori in comparison to European New Zealanders (Sundborn et al., 2007). Research has shown significant differences in cardiovascular risk factors, diabetes prevalence and unknown diabetes across ethnic groups. The main finding was that cardiovascular risk factors, morbidity and mortality were increased for Pacific people compared to European New Zealanders (Sundborn et al., 2008). Further research confirms that Pacific people and Maori have higher rates of cardiovascular disease and diabetes to that of their European counterparts (Kenealy et al., 2008).

Reducing the incidence of CVD and diabetes in the population, plus reducing inequalities in health status across regions and between ethnic groups are priorities for the New Zealand Ministry of Health (Ministry of Health, 2000). The Ministry purposely targeted better diabetes and cardiovascular services (Ministry of Health, 2012). The screening guidelines for prediabetes and how lifestyle factors can be modified to prevent CVD and diabetes, are well described in the current New Zealand Primary Care Handbook (New Zealand Guidelines Group, 2012). This document is clear acknowledgment that these two conditions, CVD and diabetes, are interconnected.

The emphasis on prevention is in itself, a driver for more research to concentrate on the development of cardiovascular disease and/or prediabetes in which ever order they may occur. An important component in the prevention of further cardiac events or development of diabetes is in understanding the patient’s perspective, how they experience and make meaning of these events. This research focuses on this patient perspective.

### **1.3.2 Prediabetes and insulin resistance**

Prediabetes (or previously termed impaired glucose metabolism) is the umbrella term for impaired fasting glucose (IFG), impaired glucose tolerance (IGT) and type 2 diabetes. The literature emphasises how during the progression of impaired glucose metabolism, islet  $\beta$  cells are overburdened with nutrient excess resulting in inadequate release of insulin to cope with ‘over

nutrition' (Nolan, Damm, & Prentki, 2011) resulting in a deficiency of insulin secretion, a growing resistance to insulin action or a combination of both (Kahn, 2003; Skyler, 2004). The natural course of events for insulin resistance to progress to type 2 diabetes is dependent on a number of factors: the degree of insulin resistance and how depressed insulin secretion is, strength of family history for type 2 diabetes, age, being overweight and an inactive life style (DeFronzo & Abdul-Ghani, 2011). Current research shows that in many cases, diabetes can be postponed or even prevented with consistent changes to lifestyle (Aroda & Ratner, 2008; DeFronzo & Abdul-Ghani, 2011).

Common clusters of research around cardiovascular disease and impaired glucose metabolism are concerned with insulin resistance and glucose intolerance found at admission to hospital with an acute myocardial infarction without a previous diagnosis of diabetes mellitus (Choi et al., 2005; Hsu et al., 2007; Ishihara et al., 2006; Norhammar et al., 2002; Wallander et al., 2005). The reverse has also been researched i.e. the prevalence of people with type 2 diabetes who develop cardiovascular events as a consequence of macrovascular disease (Fowler, 2008). A common thread of research has been to determine prevalence of hyperglycaemia on admission to hospital (Krebs, Robinson, Smith, & Toomath, 2000), or for elective cardiac procedures such as cardiac catheterisation (Harding et al., 2006). A more recent coronary angiographic study found that prediabetes is likely to be a risk factor for coronary artery disease (Kurihara et al., 2012).

There is no one option of progression from one pathophysiological state to the other, but the literature focuses on the intersect of cardiovascular disease and prediabetes (Grundy, 2012). The first option is that both insulin resistance and cardiovascular disease may occur simultaneously due to a common antecedent. The second option maintains that insulin resistance and its progression to diabetes, the underlying process itself is a precursor to cardiovascular disease. Currently there is no clear understanding of the pathophysiological development of cardiovascular disease as an antecedent to insulin resistance.

The origin of cardiovascular disease and prediabetes has a shared pathophysiology (Bartnik, et al., 2007; DeFronzo & Abdul-Ghani, 2011; Grundy, 2012). The near simultaneous occurrence of cardiovascular disease and impaired glucose metabolism is more latterly documented (Bartnik, et al., 2007; De Caterina, et al., 2010), researched (Bolk et al., 2001; Harding, et al., 2006), and guidelines established (Rydén et al., 2007). The cluster of risk factors and anomalies linked to insulin resistance examined over the last four decades are also linked to cardiovascular disease: impaired glucose tolerance, increased BMI, dyslipidaemia (as related to atherosclerosis), high blood pressure, increased inflammatory markers (such as C-reactive protein), dysfunction of vascular endothelium and dysfunction in clotting (Lamendola, 2008; Reaven, 1988, 1995). Furthermore cardiovascular events increase as insulin resistance is augmented (Verhagen et al., 2011). In the end prediabetes (as IFG and

IGT) is associated with increased risk of CVD, and increased cardiac events. In a current systematic review, 18 papers were reviewed and showed that IFG and IGT are linked with a 'modest' increase in the risk of cardiovascular disease (Ford, Zhao, & Li, 2010). Five longitudinal studies demonstrating the link between insulin resistance or prediabetes (impaired glucose metabolism) and CVD are summarised in Table 1.2.

The studies presented in Table 1.2 are comparative longitudinal or case-control studies. Prevalence is a feature of all these studies, and a primary indication is that trends for CVD and diabetes are imminent if cardiometabolic risk factors (shared risk factors for impaired glucose metabolism and CVD) are not managed in a timely manner. People with type 2 diabetes hospitalised for first-time myocardial infarction had increased mortality, and their estimated survival rate was only 50% (Donnan et al., 2002). Further evidence shows that 80% of people with diabetes die of macrovascular complications (Triplitt & Alvarez, 2008). Hyperglycaemia and diabetes mellitus are both responsible for growing global trends in morbidity and mortality. These trends are due to the direct effects of hyperglycaemia and diabetes causing cardiovascular and kidney disease (Danaei et al., 2011; Danaei, Lawes, Vander Hoorn, Murray, & Ezzati, 2006). Hence there is good accumulating data confirming the link between high blood glucose and further cardiac events (Bartnik, et al., 2007).

From the international epidemiological studies summarised in Table 1.2, the evidence shows metabolic risk factors are consistently linked with cardiovascular disease and diabetes. On the strength of these large longitudinal studies, the American Diabetes Association and American Heart Association have made numerous appeals to reinforce a need to identify and manage risk factors for impaired glucose metabolism and CVD, to reduce the prevalence of immediate and prospective illness (Eckel, Kahn, Robertson, & Rizza, 2006). These statements have been important to set international benchmarks and instrumental in setting New Zealand guidelines (Anscombe, Krebs, Weatherall, & Harding, 2006; New Zealand Guidelines Group, 2012) and developing cardiovascular risk profiles for New Zealanders (Wells, Riddell, & Jackson, 2010).

**Table 1.2 Longitudinal and/or comparative studies: prevalence for impaired glucose metabolism and cardiovascular disease**

Study	Country	Aim of study	N	Risk factors*:	Follow up	Findings	Reference
The Euro Heart survey on diabetes and the heart	Various European countries	Prevalence of abnormal glucose regulation in people with coronary artery disease	4196	Smoking, Hypertension Hyperlipidaemia, Diabetes Weight, Height, BMI Blood pressure, Fasting plasma glucose Total cholesterol, HDL-cholesterol, Triglycerides	Nil	Normoglycaemia less common in those with CAD	(Bartnik et al., 2004)
	15 European countries	Auditing if recommendations on coronary prevention are being followed in clinical practice by EUROASPIRE II study group	5556	Smoking, Hypertension Hyperlipidaemia, Diabetes Weight, Height, BMI, Blood pressure Total cholesterol, HDL-cholesterol, Triglycerides	Approximately 1 year after discharge, interviewed for changes in risk factors	High prevalence of modifiable risk factors, deleterious lifestyles, and lack of effective drug therapy.	(EUROASPIRE group, 2001)
DARTS/MEMO collaboration	Scotland (Tayside)	Mortality and macrovascular complications post first MI for those with type 2 diabetes	147	Smoking Hypertension Hyperlipidaemia Diabetes	Two-year event rate	People with first MI, those with T2D had higher mortality or admission for HF. Estimated survival rate is 50%.	(Donnan, et al., 2002)
Framingham study	United States of America	Macrovascular complications compared between those with or without diabetes		Smoking, Hypertension Hyperlipidaemia, Diabetes Weight, Height, BMI, Blood pressure Total cholesterol, HDL-cholesterol, Triglycerides	Compare one group (1952-1974) to another (1975-1998)(Fox et al. 2007)	Increasing CVD due to T2D over the last 50 years. Indicative of need to treat and control CVD risk factors for those with DM	(Fox et al., 2007; Kannel & McGee, 1979)
The China Heart Survey	China	Prevalence of IGM for those with CVD in China to improve management for patients	3515	Smoking, Hypertension Hyperlipidaemia, Diabetes Weight, Height, BMI, Blood pressure Total cholesterol, HDL-cholesterol, Triglycerides	Nil	Impaired glucose metabolism is common in people with coronary artery disease.	(Hu, Pan, & Yu, 2006)
Helsinki policemen study	Finland	Insulin resistance predicts risk of CHD and stroke	970	Smoking, Hypertension Hyperlipidaemia, Diabetes Weight, Height, BMI, Blood pressure Total cholesterol, HDL-cholesterol, Triglycerides And further more comprehensive measurements	22 year prospective study	Risk factor clustering for insulin resistance syndrome predicts both CHD and stroke.	(Pyörälä, Miettinen, Halonen, Laakso, & Pyörälä, 2000)

CAD = coronary artery disease, CHD – coronary heart disease, CVD = cardiovascular disease, HF = heart failure, MI = myocardial infarction, T2D = type 2 diabetes  
\*Risk factors = medical history, family history, measurement of physiological parameters

### **1.3.3 Screening and managing risk factors: CVD and prediabetes**

A risk factor is a variable linked to increased likelihood of disease. The shared traditional risk factors for CVD and IGM collectively are sometimes referred to as the metabolic syndrome, well described in the literature (Gami et al., 2007; Grundy, 2012). The literature provides excellent summaries of the interrelationship between CVD and diabetes, highlighting risk factors and shared pathophysiology (Bartnik, et al., 2007; Grundy, 2012). Continuous thorough management of cardiometabolic risk, requires constant assessment and reassessment of those risk factors (Early, 2007). The classic risk factors for cardiovascular disease comprise, gender, BMI, physical inactivity, hypertension, smoking, diabetes, reduced levels of high-density lipoprotein cholesterol, higher levels of very low-density lipoprotein cholesterol, higher levels of low-density lipoprotein cholesterol (Early, 2007; Grundy, 2007; New Zealand Guidelines Group, 2012). Lifestyle modification coupled with pharmacotherapy are the mainstay of reducing risk with the best long-term results (Early, 2007). Treating central (or abdominal) obesity has one of the most enduring effects on decreasing risk for both CVD and IGM. Weight loss of 5-10% can have a significant effect on reducing risk factor effect (National Institute of Health & National Heart Lung and Blood Institute, 2004).

Screening is a central component to secondary prevention interventions (Stanhope & Lancaster, 2004) which involves testing people considered at-risk of developing certain pathophysiological states i.e. that are asymptomatic only to become symptomatic in time and under the right conditions. With the introduction of national guidelines for CVD, CVD with diabetes, and diabetes, health professionals have excellent information available to guide them through a rigorous screening process (New Zealand Guidelines Group, 2012). Knowing that screening tests do not constitute diagnosis, a random blood test is acceptable to initiate screening especially if screening is opportunistic (Ziemer et al., 2008). Screening and diagnosis for impaired glucose metabolism is now recognised to be best achieved with measurement of plasma HbA1c (New Zealand Society for Study of Diabetes Executive, 2011), particularly as screening can rely on a random blood sample.

In the past five years there has been interest in glycated haemoglobin as an independent risk factor for cardiovascular disease (Elley, Kenealy, Robinson, & Drury, 2008). In New Zealand HbA1c levels are now in routine use for screening and diagnosis of diabetes: plasma HbA<sub>1c</sub>,  $\geq$  50 mmol / mol as diagnostic for diabetes, and HbA<sub>1c</sub> 41-49 mmol/mol indicative of 'pre-diabetes' (New Zealand Society for Study of Diabetes Executive, 2011). Current recommendation is that plasma HbA<sub>1c</sub> and fasting blood glucose be used together to target those people considered at risk (Heianza et al., 2011; New Zealand Guidelines Group, 2012), for

example those attending elective coronary angiography (Harding, et al., 2006; Wascher, Sourij, Roth, & Dittrich, 2004).

Health professionals such as nurses are very likely to be involved in health care of people with CVD and prediabetes, across health sectors. The following section provides some insight into how nurses are currently involved in identifying and managing people with this combination of diagnoses.

#### **1.4 Nursing practice and research: CVD & prediabetes**

The nursing literature reflects comprehensive understanding of local and global trends of non-communicable conditions such as prediabetes and diabetes (Hjelm, Mufunda, Nambozi, & Kemp, 2003; A. Reed, 2010; Smith, 2010), with CVD (Lamendola, 2008). People with cardiometabolic risk factors are frequently in hospitals and community care settings where nurses work. For this reason, there are frequent opportunities for nurses to work with individuals and groups to counter risk factors that potentiate complex illness. Screening is a common process used to reveal risk factors, and is a common adjunct to assessing needs and outcomes in advanced nursing practice (Furze, Donnison, & Lewin, 2008; Meires & Ledbetter, 2012). A good environment to capture those with prediabetes is the work setting, where healthy lifestyles can be encouraged and supported (Chen & Lin, 2010).

Nurses are involved in team research contributing directly to the science of insulin resistance and impaired glucose metabolism (Knobler, Abbasi, Lamendola, & Reaven, 2011). The nursing literature describes the pathophysiology of CVD, a regular sequelae of insulin resistance or diabetes (Gordon, 2004; Lamendola, 2008). The high prevalence of undetected diabetes or impaired glucose metabolism found in patients by health professionals working in cardiac-specific clinical settings indicates a need for vigilance in daily clinical work (Bartnik & Cosentino, 2009). This finding is highly relevant to nurses working in advanced practice settings such as cardiology and endocrinology where risk factors for both diabetes and CVD should be consistently screened for in adults (Borgman & McErlean, 2006; Knobler, et al., 2011; Lamendola, 2008), and adolescents (Kayyali, 2012).

A further theme in the nursing literature is to raise the awareness of population-based health to avoid development of diabetes and complications. Research supports improving people's knowledge about diabetes and becoming more proactive about prevention (Hjelm, et al., 2003; Hjelm, Nyberg, Isacson, & Apelqvist, 1999). Best practice recommendations concentrate on improving nursing care for those with CVD and diabetes (Gordon, 2004). Population health research is also lead by nurses (Neira, Hartig, Cowan, & Velasquez-Mieyer, 2009). Neira and

team (2009) have particular interest in screening for impaired glucose metabolism in Hispanic people as their prevalence rate for diabetes is 1.7-1.8 times greater in relation to non-Hispanic counterparts. Similar patterns are reflected in different sectors of the New Zealand population as described in section 1.3.1. Nurses would gain much by careful observation of these patterns of prevalence, and initiating appropriate forms of prevention and clinical management.

Nurse leaders in New Zealand are encouraging nurses to look at the broader context of both their practice and the service delivery (Snell, 2011). Although Snell comes from the standpoint of service support for those with diabetes, the issues she raises are just as relevant for those with CVD and prediabetes. Snell states in her editorial, that nurses are philosophically equipped to work with the “person as a whole” (2011, p. 2) which is vital to successful health care of those with complex illness such as CVD and prediabetes.

This doctoral study aims to consider the experience of risk factors, and disentangle the meaning given to risk factors by people living with complex illness. The expression of their experiences and interpretations assists researchers to focus on constructing their own interpretation, of what people know about their complex illness as risk factors and comorbidity evolve, accumulate and exacerbate their condition.

The research is part of a larger Health Research Council/District Health Board (HRC/DHB) translational study entitled “Reduced incidence in cardiovascular events (RICE) study”. The aim of the RICE study was to improve outcomes for individuals, by providing structured care once discharged home (Krebs et al., 2013). Information concerning the RICE study and the focus of the doctoral research are explained in the next section.

### **1.5 HRC/DHB funded translational research: Reduce Incidence in Cardiovascular Events (RICE) study**

Prediabetes (definition in section 1.3.2) is defined by HbA1c and fasting blood glucose measurement as per New Zealand Society for Study of Diabetes position statement 2011(see appendix 1). Prediabetes is a major risk factor for developing type 2 diabetes, plus microvascular disease (retinopathy) and macrovascular (cardiovascular) disease (Aroda & Ratner, 2008). Admission to a Cardiac Care Unit with acute coronary syndrome (ACS) also found to have high blood glucose, is a significant independent risk factor for long-term prognosis and mortality (Bartnik, et al., 2007; Suleiman et al., 2005) as described in Sections 1.3.2. and 1.3.3. A similar picture is found in New Zealand for patients admitted for elective cardiac catheterisation, who demonstrated impaired glucose metabolism and are at higher risk for prospective cardiac events (Harding, et al., 2006; Krebs, et al., 2000).

Funding was secured for a twelve month translational study, from the HRC and DHB (HRC 09-586). The study was a collaboration between Massey University (Associate Professor Rachel Page and Kim van Wissen), the Endocrine and Diabetes Research Centre at Wellington Regional Hospital (Dr Jeremy Krebs and Margaret Ward) and Heart and Lung Unit at Wellington Regional Hospital (Dr Scott Harding). The collaborative team worked on the proviso that impaired glucose tolerance (a subset of prediabetes) is a good predictor of prospective cardiovascular events (Bartnik, et al., 2007) and potential development of type 2 diabetes (Grundy, 2012). The aim of the study was to demonstrate that managed lifestyle modification can reduce the incidence of diabetes and further cardiac events for at-risk groups, by optimising and managing the resources that are already in place within the health care sector. The at-risk group was identified as people with acute coronary syndrome (ACS) and prediabetes.

This prospective intervention study (RICE) was run over nine months as the funding was for a year only. People admitted to a regional Heart and Lung Unit with ACS or elective cardiac procedure also found to have a fasting plasma glucose  $\geq 6.1$  mmol/L and/or glycated haemoglobin (HbA1c)  $> 6\%$  (42 mmol/mol) were included in the study. Participants had baseline biochemical (fasting blood glucose, HbA1c, full lipid profile) and physiological (weight, waist and hip circumference, height and blood pressure) measures taken while in the unit. They were also asked to complete a SF36 questionnaire (Ware, 2000; Ware, Kosinski, & Keller, 1994) to ascertain the state of their general health. Glycated haemoglobin was used as a measure for improvement in control of glucose metabolism over the 9 months of the study. The participants were randomised into a control or intervention group. Thirty three participants were recruited at time zero (in hospital). At approximately nine months after discharge all the participants had all the procedures repeated as at time zero. This included the same biochemical and physiological assessments, as well as completing a SF36 questionnaire and in depth interview. Twenty nine participants were reinterviewed (interview 2), two participants had dropped out of the study and two people had died between interviews.

The participants were identified from a large pool of people covering a geographical area spanning the lower North Island, but only those people in the immediate Wellington area were recruited. The participants were recruited from 21 September 2009 till 16 June 2010. Seeking out this cohort of patients for the study took approximately 3 hours daily for 181 days. Over 2010 and 2011, interview 2 plus biochemical and physiological measurements were collected, and the data set completed in July 2011.

There were a number of reasons why the recruitment phase was protracted. There were difficulties engaging staff to order fasting glucose for all admissions to the unit even though this it was considered part of usual admission procedure. Glycated haemoglobin blood levels were batched and processed twice a week in the hospital laboratory. This in turn meant ‘finding’ potential participants from HbA1c positive results would sometimes arrive after potential participants had been discharged. The unit was also a potential source of participants for other cardiac studies and potential participants could be of interest for up to three other studies. All these obstacles were all overcome but did add to the time span of recruitment.

The baseline characteristics of the RICE study (Krebs et al., 2013) are shown in Table 1.3, the clinical and biochemical measurements taken during the time of hospitalisation and at nine months after discharge are in Table 1.4., and socio-demographic details for the RICE study and this qualitative research are shown in Table 1.5.

**Table 1.3 Baseline characteristics for RICE study\* participants**

<b>Baseline Characteristic</b>	<b>Whole participant group (n=33)</b>
Males, n (%)	25 (75)
Age years, mean (SEM)	63.1 (2.1)
Index Acute Coronary Syndromes, n (%)	
STEMI	14 (42)
NSTEMI	10 (30)
Unstable angina	5 (15)
MI	3 (9)
History of prior cardiovascular disease, n (%)	23 (70)
Glycated Haemoglobin , mean (SEM)%	6.10 (0.08)
mmol/mol	43.04 (0.92)
Fasting blood glucose mmol/L, mean (SEM)	6.10 (0.15)

\*With permission: Krebs, J. D., Van Wissen, K. A., Harding, S. A., Ward, M. A., Marra, B., & Page, R. A. (2013). An intervention trial for patients with hyperglycaemia and acute coronary syndrome: How effective is lifestyle advice? *Primary Care Cardiovascular Journal*, 6(2), 72-75.

STEMI – ST elevation myocardial infarction. NSTEMI – Non ST elevation myocardial infarction. MI – myocardial infarction.

**Table 1.4 Clinical parameters on admission and nine months after discharge for RICE study\* cohort**

Parameter	Whole participant group	
	Baseline n=33	9 months n=29
<b>Body Mass Index (kg/m<sup>2</sup>), mean (SEM)</b>	29.6 (0.8)	30.04 (0.89)
<b>≥ 30 kg/m<sup>2</sup>, n(%)</b>	15 (47%)	14 (52%)
<b>Waist (cm)</b>	103.3 (2.3)	104.5 (2.3)
<b>Blood Pressure (mm Hg), mean (SEM)</b>		
<b>Systolic</b>	124.2 (3.4)	132.84 (3.36)
<b>&gt;140 mm Hg, n (%)</b>	3 (9%)	15 (9.4%)
<b>Diastolic</b>	73.6 (1.7)	81.26 (2.14)
<b>Current Smoker, n(%)</b>	11 (34%)	8 (26.7)
<b>Fasting Plasma Lipid Profile</b>		
<b>Total Cholesterol (mmol/L), mean(SEM)</b>	4.86 (0.21)	4.34 (0.20)
<b>&gt;4 mmol/L, n(%)</b>	18 (60%)	15(51.7%)
<b>LDL Cholesterol (mmol/L), mean (SEM)</b>	2.62 (0.19)	2.11 (0.18)
<b>&gt;2 mmol/L, n(%)</b>	16 (70%)	12 (42.9%)
<b>HDL Cholesterol (mmol/L), mean (SEM)</b>	1.16 (0.07)	1.38 (0.09)
<b>&lt;1 mmol/L, n(%)</b>	10 (33%)	5 (17.2%)
<b>Triglycerides (mmol/L), mean (SEM)</b>	1.89 (0.27)	1.52 (0.15)
<b>&gt;1.7 mmol/L, n(%)</b>	13 (45%)	10 (38.5%)
<b>Total:HDL Cholesterol Ratio</b>	4.59 (0.33)	3.37 (0.20)
<b>&gt;4, n (%)</b>	17 (57%)	6 (20.7%)

\*With permission: Krebs, J. D., Van Wissen, K. A., Harding, S. A., Ward, M. A., Marra, B., & Page, R. A. (2013). An intervention trial for patients with hyperglycaemia and acute coronary syndrome: How effective is lifestyle advice? *Primary Care Cardiovascular Journal*, 6(2), 72-75.

The socio-demographic information depicting the RICE study and therefore participant group for this doctoral research, are shown in Table 1.5.

The focus of my research was to examine how people with ACS also found to have a high blood glucose experience complex illness. The RICE study cohort is also the participant group for the doctoral study. The in-depth interview, performed at 0 (in hospital) and 9 months after discharge from the hospital, provided qualitative data for examining the participants experiences and interpretation of their experiences after being diagnosed with ACS and high blood glucose. This qualitative data formed the basis of an interpretive description, my research, which reveals how participants experienced and interpreted illness.

**Table 1.5 Socio-demographic description of RICE study and doctoral study participant group**

Demographic		n=33	
Sex	Male	25	
	Female	8	
Age range (years)		43-85	
Work Status	Employed	19	
	Retired or not employed	14	
Ethnicity	Pacific Island people	0	
	Maori	3	
	Chinese, New Zealand	2	
	European, New Zealand	28	
Relationship status	Single	Female	1
		Male	2
	Widow	Female	1
		Male	3
	Married	21	
	Divorced	Female	2
		Male	3

## 1.6 Overview of this thesis

This document is organised into 10 chapters. The first chapter is an introduction, stating background to the study, the research questions and aims of this doctoral study and how they relate to nursing. Chapter 2 provides a literature review on the current research related to the experience and interpretation of illness. This supports and aids justification of the research questions for this PhD study. Chapter 3 identifies and details the theoretical perspective of this doctoral research, namely how interpretivism and constructivism plus how the philosopher Hans-Georg Gadamer all contribute to both the process and presentation of outcomes of this research. Chapter 4 introduces the methodology of interpretive description, how this methodology supports clinical research, and generates a method that allows one to research in clinical settings. Chapter 5 provides an account of the methods used in data collection and analysis. Chapter 6 presents the first part of research findings, the thematic framework which sets up a presentation of deeper findings in chapters 7 and 8. Chapter 9 discusses the findings of the study. Chapter 10 is a concluding chapter presenting: a summary of findings, implications for clinical practice, contribution to nursing knowledge and an indication of potential future research.

## **Chapter 2**

### **Literature review: Constructing illness**

#### **2.1 Introduction**

The literature reviewed here is of the extant research dedicated to the combined experience and interpretation of illness. This chapter begins with an overview of the search strategy used to access literature (Section 2.2) followed by an examination of definitions of illness (Section 2.3) and a working definition of ‘illness’ for this doctoral research. The experience of illness (Sections 2.4 -2.7), what understanding people garner about their illness through interpretation (Section 2.8), and what research pulls these two aspects together is also explored (Section 2.9).

The literature was also searched for any research addressing the experience of illness when a new aspect of illness is revealed (Section 2.5). Here the interest is in the intersection of having one condition (e.g. acute coronary syndrome) and then diagnosed with another condition (e.g. prediabetes). A further angle of interest concerns the experiences people have of comorbidities and how people cope with multiple conditions (Section 2.7).

#### **2.2 Search strategy for literature review**

A variety of literature was employed to contextualise “the experience and interpretation of illness” from the perspective of the participant. The contextualization is of those with an acute coronary syndrome event with the added finding of high blood glucose. This context is very precise and searching the databases did not unearth any published research dedicated to this perspective.

An initial review of the literature at the beginning of the research revealed a growing database for “experience of those people with illness” with a variety of diagnoses. Searching for literature was achieved by using electronic databases, word-of-mouth and hand-searching during the time of the research. Electronic databases searched were Ebscohost, Medline, PubMed, CINAHL, and Google Scholar. Particular key words used in search fields were: illness or ill\*, experience, experience\*, interpret\*, nurs\*, “cardiovascular disease”, “acute coronary syndrome”, diabetes, type 2 diabetes, prediabetes, comorbidity, multimorbidity. Combinations of these key words were used to refine the search across databases. A variety of books, journals, popular publication, theses and government documents were also accessed.

### 2.3 Defining illness

Illness has been well researched and reported in the literature, and extensive links are made to illness and nursing (Benner, Tanner, & Chesla, 2009; Lubkin & Larsen, 2009; Thorne et al., 2002) and illness to nursing philosophy (Nordby, 2004). Illness is also prominent in the literature of psychology (Bendelow, 2009; Greenberg, 2007), sociology (Blaxter, 2010; Bury, 2005; Charmaz, 1991; Conrad, 1990, 1992; Williams, 1984), autobiographical critique by academics (Carel, 2008; Murphy, 1987; Oakley, 2007), philosophy (Dekkers & Gordijn, 2007; Nordenfelt, 2007) and medicine (Greenberg, 2007; Kleinman, 1988; Mol, 2002). These links are separated here for clarity, however there is a great deal of crosspollination between and beyond these disciplines which in turn further defines and redefines the complex nature of illness (Furze, et al., 2008; Twohig & Kalitzkus, 2004; Vickers, 2001), how illness acts as a conduit between health and disease (Fulford, 1993). Added to this is how illness is socially constructed (Charmaz, 1991; Conrad & Barker, 2010; Sontag, 1991) and has a significant psychosocial perspective (Bendelow, 2009).

Both older and current literature make important distinctions between disease and illness (Charmaz, 1991; Kleinman, 1988; Lubkin & Larsen, 2009). Disease relates to the pathophysiological phenomena that makes a grouping of signs and symptoms distinct from each other, where bodily composition and function are altered (Furze, et al., 2008). Illness is related to the experience of those people that live with disease (Blaxter, 2010; Lubkin & Larsen, 2009), accepting (in part or whole) the psychosocial impact of illness (Greenberg, 2007) and what meaning can be made of the experience (Frank, 1995; Twohig & Kalitzkus, 2004). Disease influences how a person copes and progresses with illness (Blaxter, 2010; Lubkin & Larsen, 2009). Equally health and illness are not mutually exclusive. Frank (1991) describes how the experience of signs and symptoms are blurred and how complicated it can be to differentiate one state over the other state: "Health and illness, wellness and sickness perpetually alternate as foreground and background. Each exists because of the other and can only alternate because of the other" (1991, p. 135). Hence illness shifts and vacillates between health and disease.

A prominent feature in the literature is the terminology attributed to illness. "Terminology matters" (Wellard, 2010, p. 2) and misuse of terms can misconstrue meaning. Wellard (2010) describes a number of terms used to describe illness as: chronic illness, chronic disease, chronic conditions. A more local New Zealand term used is 'long term conditions' (Ashworth & Thompson, 2011; Carryer, Snell, Perry, Hunt, & Blakey, 2008; National Advisory Committee on Health and Disability, 2007). From the National Advisory Committee document (2007) long-

term conditions were defined as: “any ongoing, long-term or recurring condition that can have a significant impact on a person’s life”, a definition that seeks to shift away from the medico-disease based definition of chronic illness, to include the psychosocial aspect of illness. This effectively defines illness for this doctoral study too: where a condition has an impact on one’s life; “illness being the subjective experience of ill health” (Blaxter, 2010, p. 20). Returning to Wellard (2010), she explains that without careful definition of illness it is not clear which theoretical perspective research is based upon. Note ‘illness’ stands alone in this doctoral thesis and prefixes are used when more precision is required. The definition of illness for this PhD study is provided in section 2.3.1.

Phases of illness appear in the literature on a continuum as an acute illness shifting to chronic illness and in reverse (Blaxter, 2010, p. 10), or as simultaneous phenomena wherein a person has chronic illness and develops an acute episode of illness (Bendelow, 2009). A further phase of illness is insightfully described as the “illness iceberg” (Blaxter, 2010, p. 76). Here the signals of illness may be disregarded, self-treated, or medical opinion simply not sought. The afore behaviour is common (Furze, et al., 2008) and begins to account for the shifting between acute and chronic phases of illness, or how the phases blend to give us illness. There is a repositioning away from the old axiom that health is the absence of disease, indeed illness is largely always extant (Bendelow, 2009; Blaxter, 2010; Furze, et al., 2008) or conceived as health within illness (Carel, 2008).

A further recurring theme in the literature is the dichotomisation of illness: health and illness (Oakley, 2007), wellness-illness (Jensen & Allen, 1994; Paterson, 2003) or even as health, illness and disease (Twohig & Kalitzkus, 2004). Dichotomisation is potentially counterproductive as it tends to prohibit deviation from the two (or three) given options (Thorne, Henderson, McPherson, & Pesut, 2004). It is noteworthy that today the use of the word illness may even be avoided, for example in the titles of more current books (Bendelow, 2009; Blaxter, 2010; Furze, et al., 2008) and development of government documents (National Advisory Committee on Health and Disability, 2007). The main thrust of this movement is to accentuate the positive, or foreground wellness, so that the complications and distress of illness are avoided (Paterson, 2001b, 2003). This is a symptom of our current self-help mind set where talking-up and maintaining positive face is considered essential (Thorne & Paterson, 1998).

Williams and Botti (2002) write that those experiencing illness will inevitably have some degree of comorbidity. Williams (2010) further clarifies that comorbidity is indicative of an increase in prevalence of concurrent diagnoses. Added to this the complexity of care is increased as people find themselves admitted to hospital for acute episodes of chronic illness (Grau & Kovner, 1986; Williams & Botti, 2002) or as reluctant “frequent fliers” (Nelson, 2012/2013). A pattern

of acute episodes layered over chronic conditions is part of the experience of complex illness. Williams (2010) explains that this layering becomes complicated for patients and their families required to network with various clinicians and agencies in multiple health care settings.

### **2.3.1 Definition of illness for this doctoral research**

Working with people with long-term conditions involves striving to recognise the complexity of person and illness (Carryer, et al., 2008), and work well beyond the narrow focus of disease management to manage long-term conditions (Ashworth & Thompson, 2011; Furze, et al., 2008). The definition of illness for this research refers to the complexity of illness which is in alignment with past definitions (illness being the experience of ill health) but is extended to the “perceived human experience of living with and responding to disease by those with the disease and the people who live with them” (Wellard, 2010, p. 2), which includes a personal interpretation of disease.

## **2.4 The experience of illness**

This particular section concentrates on a portion of the research question, the experience of illness. The word ‘experience’ is complicated as it has multiple meanings (Lumby, 1994). Experience is both an occurrence and a response to this occurrence. In a similar vein, the experience of illness has the attribute of having a pathological phenomenon, but because this experience is a human experience there is also an associated response to this phenomenon (Lumby, 1994). This point of occurrence and response has been recorded by educationalists (Boud, Keogh, & Walker, 1985), philosophers (Satre, 1968) and ultimately found in nursing research (Thorne & Paterson, 2000). The following subsection highlights how this literature has developed over time.

### **2.4.1 Historical readings: The experience of illness**

The literature concerning illness and how this may be experienced has its foundation in sociology, anthropology, medicine and literary critique. From these origins nursing research eventually emerged to explore the phenomena central to illness. While there is a significant body of research and prose concerning illness, this review highlights important work that remains foundational to our understanding of the experience of illness and presents a useful counterpoint to current literature.

### **2.4.1.1 Illness as metaphor**

Susan Sontag's essay written "illness as metaphor" uses hyperbole to encourage the reader to shift away from the metaphorical idiom of illness. She explains that elimination of the metaphor would allow one to experience illness such that "the healthiest way of being ill - is one most purified of, most resistant to, metaphoric thinking" (Sontag, 1991, p. 3). This is in contrast to the beginning paragraph wherein she describes that metaphorically everyone has "dual citizenship, in the kingdom of the well and in the kingdom of the sick" (Sontag, 1991, p. 3) and indeed throughout her text she constantly refers to metaphors. Immediately she presents a tension for the use of metaphor in descriptions of illness as it seems unavoidable not to use metaphor. Regardless of this inconsistency (and others made), her essay is seminal as it presents many facets of illness not openly addressed before and even today Sontag's essay is constantly referred to or critiqued when illness is under the microscope (Govan, 2004; Hanne & Hawken, 2007; Vandamme & Oderwald, 2004). The main points that Sontag developed in her inquiry are: the glamorisation of illness by using metaphor, the negative representation of illness (cancer and tuberculosis) and the rejection of myth and social institutions shaping the experience of illness.

### **2.4.1.2 Illness as a human condition**

There are many excellent depictions of illness from a variety of research disciplines. Of significance is the contribution Arthur Kleinman (1988) has made to understanding illness, a reflection upon the human condition. Kleinman, as a doctor (psychiatrist and anthropologist), elucidates illness with a more clinical focus on features such as pain and death, but also explores the broader derivatives of illness. Kleinman (1988) and Sontag (1991) both offer different interpretations of the experience of illness according to their academic background. Kleinman emphasises the psychosocial aspects of illness, while Sontag offers a socio-literal analysis. Kleinman writes: "we must inquire into the structure of illness meanings: the manner in which illness is made meaningful, the processes of creating meaning, and the social situations and psychological reactions that determine and are determined by the meanings" (1988, p. 185). The experience of illness is well embedded within their work, illuminating the experience as central, rather than incidental.

### **2.4.1.3 Other important sources of research**

Kathy Charmaz is another important contributor to the research of chronic illness from a broad sociological perspective. She developed foundational research on chronic illness from which nursing research would proliferate. In her book entitled "Good days bad days" Charmaz (1991)

persuasively articulates many enduring socio-medicalised concepts pertaining to illness still relevant today such as: chronic illness as interruption, the intrusion of illness, immersion in illness, living with chronic illness, plus illness the self and time. A similar conceptual focus is also found in Arthur Kleinman's (1988) work.

Research concerning illness grew during the 1980s and early 1990s. Research concentrated on: the 'sick role' (Charmaz, 1991), negative conceptualisations such as loss (Charmaz, 1983), suffering (Kleinman, 1988) and the perspective of the "insider" (participant) (Conrad, 1990), patients as participants attending outpatient clinics (Conrad, 1990), and the genesis of illness (Williams, 1984). These publications appeared more frequently in socio-medical journals. Researchers from the feminist, sociological and psychological academe spearheaded research concerning illness as described. Nursing research around the same topic of illness was influenced by these academic colleagues. This sets the scene for significant research development commencing around the 1990s.

#### **2.4.2 Contemporary nursing research: Experience of illness**

The research questions that drive this doctoral research are concerned with experience (Section 2.5) and interpretation (Section 2.8). The literature review in the remainder of this chapter, highlights how researchers from the nursing discipline inform understanding of the experience of illness. Even today, nursing research can be found to make direct reference to the established academics Charmaz (Thorne, et al., 2002), Kleinman (Hynes, Stokes, & McCarron, 2012; Tropea, 2012), Sontag (Thorne, et al., 2002; Tropea, 2012). Nursing as a discipline is finding its own nurse champions on this very subject.

Clinical research is an important aspect of clinical scholarship (Diers, 1995). Within the nursing discipline, various forms of research relating to the experience of illness have been undertaken over the past 25 years or more. The methodology supporting research has included life story through to pathography, all elucidating the experience of illness; a summary of examples can be found in Table 2.1. on the next page.

**Table 2.1 Examples of nursing research exploring the experience of illness**

<b>Publication Form</b>	<b>Description of research Title</b>	<b>Reference</b>
Edited books	Qualitative research Chapters presenting research concerning a particular aspect of illness	(Madjar & Walton, 1999; Morse & Johnson, 1991)
Doctoral research	Qualitative research Phenomenological methodology Pain as an embodied experience: A phenomenological study of clinically inflicted pain in adult patients	(Madjar, 1991)
Journal publication	Qualitative research using secondary analysis The structure of everyday self-care decision making in chronic illness	(Thorne, Paterson, & Russell, 2003)
	Hermeneutic methodology Fatigue and relatedness experiences of inordinately tired women	(Dzurec, 2000)
	Phenomenological methodology The life experiences of young people (13-16 years) with type 1 diabetes mellitus and their parents	(Spencer, Cooper, & Milton, 2012)
	Lifeworld methodology Living with moderate-severe chronic heart failure as a middle-aged person	(Nordgren, Asp, & Fagerberg, 2007)
	Life story I have mastered the challenge of living with a chronic disease: life stories of people with rheumatoid arthritis	(Stamm et al., 2008) not a nursing source but excellent example
	Narrative synthesis Mothering disrupted by illness: A narrative synthesis of qualitative research.	(Vallido, Wilkes, Carter, & Jackson, 2010)
	Pathography The political role of illness narratives	(Sakalys, 2000)
	Exploratory study, qualitative Informal care-giving in advanced chronic obstructive pulmonary disease: Lay knowledge and experience.	(Hynes, et al., 2012)
	Narrative 'Therapeutic emplotment': A new paradigm to explore the interaction between nurses and patients with a long-term illness	(Tropea, 2012)

While nursing research on the experience of illness burgeoned, simultaneously there was a wave of methodological critique focusing on how the experience of illness should or could be

accessed (Benner, 1994; Lumby, 1994; Morse & Johnson, 1991). As qualitative research has grown, so too have the methods for summarising this research. One such development is the metasynthesis of qualitative research which affords deeper insights into a cluster of related studies. Table 2.2 (on the next page) encapsulates some of the summarised qualitative research concerning the experience of illness.

This is a valuable tool to review a subject of interest chiefly developed in qualitative research (Sandelowski & Barroso, 2007). Table 2.2 provides a sample of summary literature examining some aspects of the experience illness. The summary of nursing research provided in Tables 2.1. and 2.2 begins to show how composite the research has become around the experience of illness and that conceptualisations are transferable across diagnoses. For example the Flanagan and Holmes literature review in Table 2.2 (on page 26) explores a number of social perceptions that are relevant to any illness not only cancer. An illustration would be that fear may cause significant others to be over protective or demonstrate avoidance behaviour toward the person with illness.

**Table 2.2 Table of summarised qualitative nursing research: The experience of illness**

	Author(s)	Aim of review	Findings
<b>Literature review</b>	(Flanagan & Holmes, 2000)	To review the social perceptions of people toward those with cancer	Social support from families and significant others is essential, and that cancer care should work to a chronic illness model of care.
	(Telford, Kralik, & Koch, 2006)	To review the concepts acceptance and denial and how they apply to living with chronic illness	Health professionals can learn much from the experiences of people with illness in terms of their response to the denial-acceptance framework.
	(Kralik, Visentin, & Van Loon, 2006)	To explore the use of the word 'transition' in the health literature	Widely used in the literature, indicating how people adapt to change over a period of time.
	(Paterson, Charlton, & Richard, 2010)	To explore the personal, contextual and social factors influencing non-attendance at chronic disease clinics.	Factors influencing attendance at clinics are highly complex and various. Nurses are advised to develop numerous strategies to counter non-attendance.
<b>Metasynthesis of qualitative research</b>	(Thorne, et al., 2002)	To summarise theoretical constructions of the experience of chronic illness.	Deconstruction of theoretical aspects of chronic illness; demonstrates and conceptualises how individual and complex illness is for patients
	(Duggleby et al., 2012)	To explore the concept of hope, and the experience older people have of hope in the context of chronic illness.	Conceptually hope is different for older people c.f. young adults. For older adults strategies are available to maintain hope in view of chronic illness.
<b>Systematic review</b>	(Goulding, Furze, & Birks, 2010)	To review RCT with interventions to change maladaptive illness beliefs in people with CVD.	Counselling or educative interventions seem to be effective in changing maladaptive illness beliefs but more convincing research is required to give definitive guidance in terms of what process works best.
	(O'Brien & Clark, 2010)	To review the use of first person illness narratives; methodological review	Methodological issues were inadequately described in research; reviewers suggested urgent consideration of a theoretical conceptual frame for this method.
<b>Integrated review</b>	(Jónsdóttir, 2008)	To review nursing care offered in nursing clinics for those with chronic phase COPD	Nursing care for this group of people are conceptualised as: Home-based care, self-management programmes, tele-health with respiratory specialization. Family support and family focus was not found in the review.
	(Neville, 2003)	To review the concept of uncertainty in the context of people experiencing chronic illness	The importance of assessing patients for 'uncertainty' and how this can be supported by health professionals for patients and their families.

RCT = randomised control trial; COPD = Chronic obstructive pulmonary disease  
CVD = Cardiovascular disease

### 2.4.3 Concepts foundational to the experience of illness

Various concepts that contribute to a greater comprehension of experience of illness have been developed and redeveloped over the years of which some are accounted for in this subsection.

Included here are both older and more contemporary concepts relating to the experience of illness. The following summary of concepts and characterisations is not exhaustive but is presented here to illustrate how they resonate with the experience of illness. All supporting research comes from the nursing literature.

Stigmatisation as a concept as it relates to chronic illness has well developed research past (Joachim & Acorn, 2000a, 2000b) and more contemporary (Flanagan & Holmes, 2000). The more contemporary conceptualisation has a more positive focus on social construction of stigma while experiencing illness. Another reintroduced concept that has continued to be researched over the last decade is that of maladaptive illness beliefs. Today maladaptive health beliefs is given a particular context of coronary heart disease (Furze, Bull, Lewin, & Thompson, 2003; Goulding, et al., 2010). Denial is another older concept that still has research developed around it's relevance to the experience of illness. In current nursing literature the experience of illness is characterised by older concepts such as hope (Duggleby, et al., 2012; Duggleby et al., 2010), or acceptance and denial (Telford, et al., 2006). What makes the newer conceptualisation different from the old is the frequent accent on congruence of concepts with a positive experience.

Contemporary concepts of the experience of illness at about the turn of the century, are often orientated toward the ideals and economic goals of primary health care such as: self-care (Thorne, et al., 2003), self-care support (Carrier, Budge, Hansen, & Gibbs, 2010; Horsburgh et al., 2010; Schaefer, Miller, Goldstein, & Simmons, 2009) and self-management (Carrier, 2009; Horsburgh, et al., 2010). Non-attendance as non-compliance (Paterson, et al., 2010) is a general feature, also found in nurse-led clinics for chronic illness (Jónsdóttir, 2008). Motivational interviewing (Rosenbek Minet, Lønving, Henriksen, & Wagner, 2011) is now considered essential to successful self-management, with primary focus on what patients can realistically manage (Furze, et al., 2008). The experience of the caregiver for those with illness is also an established concept in nursing research (Hynes, et al., 2012), and emphasises their significant role (Bee, Barnes, & Luker, 2009).

Current concepts relevant to the experience of illness have a more political dimension exposing the difference in culture between patient and the health care they access (Sakalys, 2000). They may include: empowerment (Aujoulat, d'Hoore, & Deccache, 2007; Aujoulat, Luminet, & Deccache, 2007), transition as constructed self-identity (Kralik, et al., 2006), the person as expert (Battersby, Lawn, & Pols, 2010) or 'expert patient' (Mayor, 2006). The expert patient features in New Zealand health care literature as an aspect of quality health care (Robb & Seddon, 2006). Robb and Seddon's critique alludes to self-management and self-care support but these concepts are not directly addressed.

Embodiment of illness and/or body image has been researched and presented in older literature (Charmaz, 1995; van Manen, 1998), and remains a recurring concept in more recent research in relation to the experience of illness (Clarke, et al., 2008; Håkanson, Sahlberg-Blom, & Ternstedt, 2010; Montez & Karner, 2005). The physical and emotional aspects of embodiment remain an indispensable means of understanding illness (Blaxter, 2010). A common finding is that experiences of the body constitute disturbing and inexplicable changes that may only be explained by the medical model (Kvigne & Kirkevold, 2003), but new understanding about the body should be co-created with the participant-patient to move beyond a medical model (Ironsides et al., 2003). A more current understanding of experience of illness is supported by research that turns its mind-set to holistic nursing (Craig, Weinert, Walton, & Derwinski-Robinson, 2006), or makes meaning of the individual's experience in the lifeworld by using personal reflection (Dahlberg, Drew, & Nystrom, 2001; Håkanson, et al., 2010).

Nurse researchers have been instrumental in establishing credible research that examines the experience of illness. The next section concentrates on research of the experience of illness as a singular diagnosis. The review moves on to the experience of cardiovascular disease (section 2.5.1), followed by the experience of type 2 diabetes (section 2.5.2) and ends with the review of the experience of those with prediabetes (section 2.5.3). The review was generated for these conditions as this is the context of this doctoral research.

## **2.5 The experience of illness as singular diagnosis**

Qualitative research focussed on the experience of illness has usually attended to a singular diagnosis. Sociological research by Williams (1984) is concerned with people diagnosed with rheumatoid arthritis and how they experience living with this illness. Williams refers to other pathophysiology but stays concerned with arthritis. It is notable that he refers to "symptomatology" (Williams, 1984, p. 179) which could indicate comorbidity. Nursing research has many examples similar to Williams's, where the focus is on a singular diagnosis, yet other diagnoses encroach throughout the reported research (Conrad, Garrett, Cooksley, Dunne, & Macdonald, 2006; Håkanson, et al., 2010).

For this research, a choice has been made to study a combination of events because of the consistent evidence demonstrating how comorbidity is an entrenched aspect of illness (Williams, 2004, 2010). Attention to the combination of cardiovascular disease and prediabetes is highly relevant today as there is definitive evidence the two pathophysiological phenomena

are linked and give rise to long-term illness (Bartnik, et al., 2007; DeFronzo & Abdul-Ghani, 2011).

### **2.5.1 The experience of cardiovascular disease**

Using the largest database available, Ebscohost, the words “experience cardiovascular disease” produced 14,080 results. However, these results were not solely dedicated to the experience of the patient. Experience included the experience of institutions that admitted or cared for people with cardiovascular disease. Using Ebscohost again the words “patient experience cardiovascular disease” gave 9,463 results, with experience indicating both the health care provider and the patient. For this reason the literature reviewed in this section is written by nurse researchers where possible.

The literature (since about 1990) attending to the patient’s experience of cardiovascular disease includes options such as: the experience of myocardial infarction (Girard, 1999), or specifically the experience for men (Allison & Campbell, 2009; Hutton & Perkins, 2007) or for women (Johansson, Dahlberg, & Ekebergh, 2003; MacInnes, 2006; Sutherland & Jensen, 2000; Svedlund & Danielson, 2004; White, Hunter, & Holttum, 2007). Research has endeavoured to explain initial patient perceptions once admitted with a myocardial infarction (Nakano, Mainz, & Lomborg, 2008). A main finding from research shows that hospitalisation is a particularly vulnerable time for patients, both physically and mentally.

The experience of a myocardial infarction is linked to various ongoing issues. One concern is the likelihood of living with moderate to severe heart failure (Nordgren, et al., 2007). A further issue researched is the experience of the significant other of the person who has had the myocardial infarction (E. Andersson, Borglin, Sjostrom-Strand, & Willman, 2012; Svedlund & Danielson, 2004). This latter research throws up numerous aspects related to the need for excellent communication by health professionals, as significant others could at times feel they were ‘standing alone’ being left out of essential communication.

A further topic researched was how women’s health and libido was affected after a myocardial infarction (Sundler, Dahlberg, & Ekenstam, 2009, p. 375). Women found they needed more meaningful relationships with partners, and that their relationships with partners did change either in a positive or negative way. Often women are carers and this role was reversed after a myocardial infarction. This point is demonstrated in further research (Lefler & Bondy, 2004), where women delay seeking treatment for myocardial infarction for a range of reasons (Gallagher, Marshall, & Fisher, 2010; Lefler & Bondy, 2004). Main findings are: the mixture of symptoms that women present with, woman may be older and therefore are more likely to have

chronic conditions that mask or alter acute symptoms of myocardial infarction. It is noticeable that the more current literature concerning experience of myocardial infarction is weighted toward the experience of women, partly due to a more comprehensive understanding of physical and mental issues that occur during and after menopause (Lefler & Bondy, 2004).

An important aspect of research development has been to comprehend how patients make clinical decisions about themselves. Kirchberger and colleagues set out to understand how patients' interpretation of their symptoms of myocardial infarction influenced them to seek medical treatment (Kirchberger, Heier, Wende, Scheidt, & Meisinger, 2012). This study was comparable to the review described in the above paragraph (Lefler & Bondy, 2004), however the latter review focussed on females only. A further study researched how patients interpret symptoms of their myocardial infarction and how their interpretation contributed to personal theories of illness (Gassner, Dunn, & Piller, 2002). This point relates more to the interpretation of illness reviewed in section 2.8 later in this review. Both studies concentrated on how patients made sense of their bodies and how symptoms are misinterpreted.

Another aspect of the experience of myocardial infarction is that of lifestyle changes people are encouraged to make when they are recovering in hospital and at home which is not well reported in the literature. Research (Condon & McCarthy, 2006) highlights many of the usual lifestyle changes expected. The study focuses on the need for primary care services and health professionals to support patients later after discharge when patients run into difficulties in managing multiple lifestyle changes and the discord of returning to the status quo (Condon & McCarthy, 2006).

This section of the review has stayed with the experience of myocardial infarction rather than include the often simultaneous experience of unstable angina or acute congestive heart failure in living with cardiovascular disease. This aggregation was not intended; rather this is how the literature has presented itself.

### **2.5.2 The experience of type 2 diabetes**

Using the largest database available, Ebscohost, the words "experience diabetes" produced 14,704 results, indicating this partition of experience has been well investigated. The experience of diabetes has been well researched by nurses (Paterson, Thorne, Crawford, & Tarko, 1999; Paterson, Thorne, & Dewis, 1998; Thorne & Paterson, 2001).

One significant aspect to the research of the experience of diabetes, is the need to work toward lifestyle changes (Malpass, Andrews, & Turner, 2009). The study by Malpass and colleagues

was a random controlled trial of 30 participants with a diagnosis of diabetes in the last 6 months. Participants were randomised to usual care, intensive dietary advice or intensive dietary advice with intensive physical activity. This change in lifestyle was to accommodate a diet for weight loss or balance and making time to exercise. The aim was to see if making numerous lifestyle changes was advantageous or not. Participants were interviewed in depth at six and nine months, with no collection of physical or biochemical data. Researchers (Malpass, et al., 2009) found all three groups had made changes to their diet and activity levels, not one or the other. The principal finding was that slippage in diet was offset by increasing levels of physical activity regardless of which participant group participants were in. Participants inadvertently individualised their own plan for diet and physical activity according to a needs basis. An important finding was that increasing levels of physical activity acted as ‘gateway behaviour’, having a positive effect on other behaviour, especially when people are asked to make multiple lifestyle changes.

For some women, living with type 2 diabetes, there is a mismatch between knowledge and behaviour about their diagnosis (da Silva, Hegadoren, & Lasiuk, 2012). This incongruence may be due to the lack of understanding of how individuals react over time to living with a diagnosis such as type 2 diabetes (Griffiths et al., 2007). Griffiths points out that patient needs change according to the experiences people have living with diabetes. Their needs are diverse, which is in agreement with other research focussed on self-management (Rosenbek Minet, et al., 2011).

Outcomes of patient education for those with type 2 diabetes especially for those with a new diagnosis, appears regularly in published research (Adolfsson, Starrin, Smide, & Wikblad, 2008; Kneck, Klang, & Fagerberg, 2011). A primary issue is to involve patients in their own care (Kneck, et al., 2011; van Dam, van der Horst, van den Borne, Ryckman, & Crebolder, 2003). Principal mechanisms to achieve patient involvement are by self-management plans (Rosenbek Minet, et al., 2011) and/or self-care (Paterson, Thorne, & Russell, 2002; Thorne & Paterson, 2001). These self regulated options have been well researched from a service point of view (Gazmararian, Ziemer, & Barnes, 2009), and thoroughly reviewed (Gary, Genkinger, Guallar, Peyrot, & Brancati, 2003; Norris, Lau, Smith, Schmid, & Engelgau, 2002). Research emphasises that future inquiries should consider how these programmes work for individuals (Paterson, et al., 1998), and how successful they are long term (Norris, Engelgau, & Venkat Narayan, 2001; Norris, et al., 2002). It is worth noting that Norris et al. (2001) argue in their review there is insufficient emphasis in patient care that patients should be aware of the comorbidities linked to type 2 diabetes, a primary example being cardiovascular disease. The experience of participating in these health care services from the patients’ perspective requires further research (Ingadottir & Halldorsdottir, 2008).

Research addressing the experience of type 2 diabetes is available for different ethnic groups. This experience has been reported for urban Indians (Mendenhall et al., 2012), and urban Chinese (Tan, Chen, Taylor, & Hegney, 2012). A review by Hawthorne Robles Cannings-John and Edwards (2008) finds appropriate educational options for ethnic groups is wanting, especially if ethnic groups are in the minority (Lirussi, 2010). This is also reflected in the New Zealand literature, specific ethnic groups such as the people from Pacific islands having specific needs, particularly around maintaining culturally safe services (Tapu-Ta'ala, 2011).

This section on the subject of the experience of type 2 diabetes has been written in view of the paucity of research about the experience of prediabetes. What follows is a review of research currently available to address the experience of the latter.

### **2.5.3 The experience of prediabetes**

Using the database Ebscohost, the words “experience prediabetes” produced twenty three results. A number of results were based on the experience of screening initiatives or health delivery services (Shaikh, Hanif, Kashif, & Humera, 2011). The research describing prediabetes is currently more orientated to biomedical and epidemiological research which has in part been described in Chapter 1 (Section 1.3) of this thesis.

Research about the experience of this particular cohort of people reveals the experience of screening and diagnosis (Troughton et al., 2008), what people come to know about the condition (Evans, Greaves, Winder, Fearn-Smith, & Campbell, 2007), and health care for prediabetes (DeFronzo & Abdul-Ghani, 2011). None of these sources are from reported nursing research. One study by nurses explores the experiences of people with prediabetes (Andersson, Ekman, Lindblad & Friberg, 2008). In their study eight participants were interviewed about their experiences. Participants worked with their new diagnosis but needed support in realising what the potential diagnosis, type 2 diabetes, meant in terms of possibilities and obstacles. A further finding was the requirement for clear dialogue between health professionals and patients that acknowledged the patient experience.

Nurses work in clinical settings that are important health care locations to identify people with prediabetes, and to avoid progression to further multiple morbidity. How people experience and live with this new diagnosis is potentially an important research opportunity and is a central aim of this research.

## **2.6 The experience of living with a new diagnosis**

This section focuses on the research reporting how people experience a new diagnosis i.e. the critical time that they receive the news they have prediabetes, type 2 diabetes or even CVD, where a health professional announces that the patient has a new diagnosis. There is only limited research with a focus on the point in time immediately after a new diagnosis is announced (Kneck, et al., 2011). Kneck and colleagues undertook a study using a qualitative descriptive design to learn about how 13 people with a new diagnosis of diabetes experienced the first 2 months of their diagnosis. They found that people are driven to find out more about the condition through their own experience and self-reflection, and that participants embark upon a learning process of “inner dialogue between the self, the body and the life” (Kneck, et al., 2011, p. 558). Participants needed to grasp a new reality, a new understanding of self, body, lifestyle, and that there would be periods when confidence was rattled. As people are diagnosed with diabetes their need for information is great at the time of diagnosis. People make a point of seeking out information, a finding also found by Paterson and Sloan (1994) in their research.

The Andersson Ekman Lindblad and Friberg (2008) study revealed that people with prediabetes needed continued support and dialogue with health professionals to avoid the potential outcomes of prediabetes. This finding of continuing dialogue was also established by the Kneck Klang and Fagerberg (2011) research, indicating that people needed to adapt to a new reality and internalise lifestyle changes. Both Andersson et al. (2008) and Kneck et al. (2011) found people benefited most from health services and health professionals that were responsive to and perceptive of their specific needs at the time of diagnosis.

## **2.7 The experience of comorbidity as complex illness**

Comorbidity as coexistence of disease states, features in nursing research highlighting that nursing care should revolve around the multifaceted needs of patients (Giddings & Roy, 2008). Minnee and Wilkinson (2011) describe how people aged 65 years and over, presented to a New Zealand emergency department with 3.4 comorbidities on average. In research by Williams et al. (2007), comorbidity was often not considered by nursing staff, hence care for the whole patient was not evident. In this study, patients with osteoarthritis and other conditions (three of more comorbidities, which comorbidities were not stated), in hospital for knee joint replacement, were expected to have the same clinical pathway of recovery as a person with osteoarthritis only. Medical research demonstrates that often comorbidity is undertreated (Janssen, Spruit, Uszko-Lencer, Schols, & Wouters, 2011). Ultimately comorbidity affects general well-being of patients, delays recovery, and extends the period of hospitalisation (Williams, et al., 2007).

Comorbidity is an expected experience of chronic illness (Williams & Botti, 2002), especially when concurrent diagnoses increase in frequency (Williams, 2010). Having one condition does not protect a person from developing further conditions. Often secondary conditions develop as a result of the primary pathology, especially if there is a clear interconnecting pathophysiology to this outcome (Seeman, Guralnik, Kaplan, Knudsen, & Cohen, 1989). For example it is well recorded that diabetes invariably will cause cardiovascular disease (Bartnik & Cosentino, 2009; Bartnik, et al., 2007). Complex care becomes a reality as people find themselves admitted to hospital for acute episodes of illness layered over their chronic illness as comorbidity (Grau & Kovner, 1986; Williams, 2004; Williams & Botti, 2002). This makes the experience of illness complex too. Current research shows there is continued fragmentation in most aspects of care for those with comorbidity, particularly for older adults (Minnee & Wilkinson, 2011). Fragmentation is a recurring feature for those people that need to connect with multiple health care settings to manage complex illness themselves (Williams, 2010). The key is to prioritise and that one health issue is dealt with at a time (Morris, Sanders, Kennedy, & Rogers, 2011). Wilkes et al. (2008) found that patients were satisfied with community health care usually because nurses were experienced, understood how to prioritise and knew how to promote self-management to avoid hospital readmissions.

The research literature dedicated to the concept comorbidity extends beyond the nursing discipline. From this literature comorbidity has a number of synonyms: multiple chronic conditions (Clarke & Bennett, 2012; Clarke, et al., 2008), coexisting disease as vulnerability (Weiss & Hutchinson, 2000), second chronic illness (Collins & Reynolds, 2008), and multimorbidity (Townsend, 2012). A further point of language is made here. A person will experience (one) illness which may be comprised of various disease states. Reported research muddles this point, reporting participants have “more than one chronic illness” (Whittemore & Dixon, 2008, p. 181) when it more correctly could state participants have more than one disease state as illness. For the purposes of this research, illness includes one or many diagnoses, which effectively ensures the experience of illness is complex and various.

Table 2.3 (on page 35) summarises some of the research found in the non-nursing and nursing literature that examines the experience of living with comorbidity and also highlights which actual diagnoses constitute comorbidity.

**Table 2.3 The experience of living with comorbidity: Nursing and non-nursing literature**

<b>Authors</b>	<b>Aim of research</b>	<b>Findings of research</b>
(Willgoss, Yohannes, Goldbart, & Fatoye, 2011) Nursing	To investigate the experience of living with comorbidity as anxiety and COPD, from a patient's perspective	The quality of life was affected by anxiety causing isolation and avoidance of social and daily activities. Participants stated there was overlap of symptoms for both COPD and anxiety.
(Weiss & Hutchinson, 2000) Nursing	To investigate what aspects of care affect cooperation with management of diabetes and hypertension	External and internal warnings concerning their vulnerability were noted by participants. External warning was offered by family friends and health professionals. Internal warnings were significant in ensuring cooperation with treatments.
(Clarke, et al., 2008) Non-nursing	To investigate health issues of comorbidity, by examining body image of older adults with five or more chronic conditions	Provides a different lens to look at the embodied experience of multiple chronic conditions in later life. Both men and women had their daily life and sense of identity affected. Multiple morbidity works together with successful aging and staying healthy. No specific conditions were referred to.
(Verbrugge, Lepkowski, & Imanaka, 1989) Non-nursing	To consider various combinations of conditions in terms of impact on disability	High prevalence conditions like arthritis have a lower impact in comparison to conditions that are less prevalent such as osteoporosis. Combinations such as cerebrovascular disease and hip fractures increased disability again. This paper is seminal in identifying the need to consider comorbidity outside of medicine. Verbrugge et al. does not include the experiences of comorbidity.
(Vogeli et al., 2007) Non-nursing	To review the literature for prevalence, outcomes, patient management and costs related to multiple morbidity	This review finds that there is little information about outcomes and cost or prevalence. This review advises that combinations of conditions seem to work in tandem, and that should concentrate on these recurring combinations. This review does not include a review of the experience of multiple chronic conditions.
(France et al., 2012) Non-nursing	To identify prospective cohort studies about multimorbidity in primary care to establish: key findings, methodologies used and where the information gaps are	This review found: multimorbidity increases cost of health care and service use. No studies focussed on prevalence, cultural or socioeconomic factors. No studies focussed on patient experience, and no qualitative data was collected.

Table 2.3 does not represent the exhaustive research concerning comorbidity but does highlight the lack of focus on the experience of comorbidity. Today there is greater awareness that comorbidities should and can be researched as a combination of pathophysiological events

(Bartnik, et al., 2007; De Caterina, et al., 2010). Systematic reviews already highlight this point of heterogeneity in diagnosis and health care (de Bruin et al., 2012; Marengoni et al., 2011). This niche can be extended to include qualitative research too so a more comprehensive picture can be developed around comorbidity, especially around the patient perspective (Clarke, et al., 2008; Collins & Reynolds, 2008; Weiss & Hutchinson, 2000; Whitemore & Dixon, 2008). The aim of this research is to add to the patients' voice, explore further their experience and interpretation of illness.

The following section takes another portion of the research question (section 1.2), exploring the literature around the interpretation of illness. The interpretation here refers to interpretation by the person with illness.

## **2.8 The interpretation of illness: Patients' perspectives**

Research directly concerning people's interpretation of their illness has gradually grown over the last twenty years in the nursing discipline. The word interpretation in the research literature is usually indicative of methodological perspectives underpinning the research (Thorne, 1999, 2008), rather than interpretation of the experience by the participant. This point of clarification is important as later in this doctoral thesis an explanation is developed around the researcher's effort of interpretation.

### **2.8.1 Interpretation: A definition**

Paul and Elder wrote that most if not all reasoning contains inferences and interpretation "from which we draw conclusions and give meaning to data and situations" (2006, p. 116). It is an act of "clarifying, explicating, or explaining the meaning of some phenomenon" (Schwandt, 2007, p. 158). Interpretation for this research is mainly synonymous with meaning making of illness, "ways of coping with suffering and loss, and ways in which nursing and medical care can be more responsive to patients' understanding of their disease and experience with illness" (Benner, et al., 2009, p. 373). To interpret is to present "one's own conception of, to place in the context of one's own experience" (Paul & Elder, 2006, p. 490), thus interpretation may not always be factual, or reflect skilled reasoning. Therefore a patient may develop levels of experiential knowledge but this is dependent on the calibre of interpretation they place on their experiences. The context of this doctoral research is illness. Experience and interpretation of illness are natural precursors to knowledge of illness. This knowledge is otherwise described as "experiential knowledge" (Caron-Flinterman, Broerse, & Bunders, 2005) or "experiential expertise" (Civan, McDonald, Unruh, & Pratt, 2009; Leong & Euller-Ziegler, 2004).

It is important to clarify what knowledge is in terms of this research. In the previous paragraph it was stipulated that experience forms a base for interpretation, which in turn evolves as knowledge. The origins and presentation of knowledge have been the subject of many generations of philosophical debate and is well recounted and summarised in the literature (Alvesson & Sköldbberg, 2009). The research reported here subscribes to knowledge not as reflected in the positivist reality, but beyond ‘objective reality’ (Denzin & Lincoln, 1994), as a moral phenomenon (Gadamer, 1960/1998). Knowledge is more than the objective world; knowledge “must be judged by its ability to accomplish something” (von Glasersfeld, 1991). “Something” is taken to mean that experiential knowledge is pivotal to living with complex illness successfully, be that success ever so modest.

To build up a definition for interpretation (from the patient or participant perspective) for this research, there is an expectation that experience together with interpretation will construct knowledge, otherwise known as experiential knowledge. The experiential knowledge will differ between participants according to historical context and levels of personal reflection.

### **2.8.2 Many interpretations of interpretation: The patients’ perspectives**

Interpretation by participants or patients is found in the social science and health literature. It appears as: a process of co-creating (Ironside, et al., 2003), understandings (Broadbent et al., 2006; Mills, 2004; Prior, 2003), making sense (Jacobi & MacLeod, 2011), finding meaning (Jacobi & MacLeod, 2011; Kralik, Telford, Price, & Koch, 2005; Lee & Poole, 2005) or making meaning (Coward, 2000; Fjelland, Barron, & Foxall, 2008). This list of concepts akin to interpretation is a sample of how research reveals people’s interpretation of their condition, thereby making meaning of their lives with illness.

An interpretation of illness can also be expressed as finding meaning. In finding meaning Lee and Poole (2005) described this as a coping strategy common to those people experiencing illness and is likely to be part of a larger coping strategy. Similar research (Jacobi & MacLeod, 2011) highlights the need to make sense of illness. People with illness question their predicament, this is part of being human. This same line of interpreting illness is described by Coward (2000). Coward writes and researches from a psychological perspective of exploring existential meaning in illness. She finds that some people with illness do not find meaning from their ill health while others do perceive meaning regardless of the severity of their chronic illness.

An example of research that brings together experience and interpretation is the work by Ironside (2003) wherein co-creation of understanding is developed with participants as part of the research team. Ironside et al. undertook research underpinned by Heideggerian hermeneutics, methodologically describing common experiences of the participants. It also engendered shared meanings of living with illness as co-created by teaching staff and students as they listened to the stories of participants experiencing illness. All three (participants, students and teachers) together interpret meaning using Heideggerian hermeneutics. The process is important because it shows how the work shifts between participants telling their patient experiences and how the research group collectively make sense of the patient experience and further create “practical knowledge” (2003, p. 171). Ironside et al. have created a product (interpretation) from a process (co-creating) about experiences of illness. This doctoral research creates a product (interpretation) from a process (interpretive descriptive synthesis) about experiences and interpretation of complex illness (as CVD and prediabetes).

## **2.9 The experience and interpretation of illness**

Boud et al. pose questions highly relevant to the principal questions of this research: “what is it that turns experience into learning?” and “what specifically enables learners to gain the maximum benefit from the situations they find themselves in?” (Boud, et al., 1985, p. 7). These questions may be extrapolated out to consider how ready are patients to learn from their illness and how this learning may come about as a collaborative effort (Lawrenson, Joshy, Eerens, & Johnstone, 2010). Experience is central to this doctoral research, in which: “learning is the process whereby knowledge is created through the transformation of experience” (Kolb, 1984). Both Boud et al. (1985) and Kolb (2005) expressed how experience is pivotal to understanding as interpretation and contributes to the development of knowledge, hence one particular aspect of knowledge relevant to this research is experiential knowledge. This in turn develops theoretical knowledge for nursing, for example a science of meaning in illness (Thorne, 1999).

Experiential knowledge finds its definition from various disciplines and a range of literature sources referring to: personal knowledge (McWilliam, 2009; Polanyi, 1958), situated knowledge (Haraway, 1988), lay knowledge or lay expertise (McClellan & Shaw, 2005), an experiential credential (Whelan, 2009), personal truth (Borkman, 1976), or personal insight (Caron-Flinterman, et al., 2005). A few references specifically made inference to patients’ experiential knowledge in the context of health care (Cagle, 2002; Caron-Flinterman, et al., 2005) and more deliberately to illness (Paterson, 2001a).

In the nursing literature, reference is made to experience and interpretation (as cocreation) of illness (Ironside, et al., 2003). It seems experience is embedded in interpretation. When treating

the symptoms of illness, of equal importance is understanding the meaning of the symptom in the context of living with illness (Ironside, et al., 2003). Therefore any research aiming to make meaning of illness would logically expose the contextualised experience too. Research aiming to elucidate patient experience and make meaning of living with diabetes was undertaken by Stuckey (2009). She used creative expression (symbols and metaphors) to find greater meaning in the patient condition. This doctoral study aimed to give credibility to how patients make meaning of their condition and is an important aspect of interpretation for both the patient and the researcher.

## **2.10 Framing up the research**

This literature review shows the gradual development of rich research for the experience of illness, and limited research in relation to the patient's interpretation of illness. The findings are summarised as follows:

1. Research concerning the experience of illness is now well established,
2. Research concerning the patient's interpretation of illness is emergent but requires more evidence to demonstrate the shift from experience to the patient's interpretation,
3. Minimal research is devoted to the experience and interpretation of people with comorbidity as illness,
4. Little research specifically looks into the experience and interpretation of illness for the person with cardiovascular disease also found to have high blood glucose or prediabetes.

Research concerning people's experiences of illness has tended to centralise around one particular diagnosis. Expanding research efforts away from a medical diagnosis, and capturing the complexity of illness, especially comorbidity, was the intent of this research. Using terms such as acute coronary syndrome, hyperglycaemia and comorbidity seem at odds with the aims of this research. The purpose of this doctoral thesis was to begin with traditional medical language and then synthesise beyond this nomenclature to a more interpreted understanding.

Additional novelty of this research lies in the combination of participants' experience and interpretation of their illness in the context of those people with cardiovascular disease also found to have high blood glucose. A further research focus was on the experience and interpretation of comorbidity as illness, to begin to represent complexity of illness. The next chapter provides an explanation of the theoretical perspective that underpins this research. This perspective is essential to structuring an understanding of the knowledge patients have constructed about their lives, living with complex illness.

## **Chapter 3**

### **Theoretical perspective of research**

#### **3.1 Introduction**

Researchers have a particular view of the world, which in turn guides the researcher to work with various research modalities. The ontological perspective of this doctoral research is that of interpretivism, that the nature of reality may be interpreted and various. The relationship between the researcher and the knower, epistemology, is constructivism. Constructivism denotes that meaning is constructed with or through the knower. For this reason interpretivism is epistemologically supported by constructivism (Denzin & Lincoln, 2005). This research is focussed on how people experience and then interpret experiences, thus coming to know how this interpretation becomes part of their constructed knowledge about illness. Chief aims of the research are to gain an understanding the world in which people live with illness, and also gain an understanding of the complexity of this constructed knowledge of illness in the context of comorbidity (cardiovascular disease and high blood glucose).

The methodology used for this research is interpretive description. Interpretive description permits insight into the worlds of people as patients, improving our understanding of multifarious clinical phenomena at an experiential level (Thorne, 2008). Interpretive description is discussed in depth in Chapter 4.

The first sections of this chapter introduce the underlying theoretical perspective that underpins this research (Sections 3.2 and 3.3). This involves acknowledgement of the philosophical writing of Hans-Georg Gadamer (Section 3.3) and Merleau-Ponty (Section 3.3.2), and how their writing fits within an interpretive tradition. Then follows an exploration of how the role of constructivism is recognised in terms of its epistemic contribution to both the ontological lens (interpretivism) and how it influences method used in this research. A discussion is developed on the notion of ‘knowledge construction’ from an interpretivist viewpoint and how this relates to patient knowledge (Section 3.5.3). Finally the notion of qualitative health research is introduced and related to this research (Section 3.6).

### **3.2 Theoretical perspective influencing the research**

All qualitative research is influenced by theoretical perspective(s). Lather (2006) writes that theoretical perspectives underscoring research are ever evolving. Lather's paper discusses the four main theoretical perspectives (deconstructivism, critical theory, interpretivism, and positivism) from various aspects to illustrate how they are dissimilar but ultimately connected (2006, pp. 38, Table 2.). Lather also expresses how theoretical perspectives "tame the wild profusion of existing things" which she quotes from Foucault (1970, xv) and states how theoretically we should make efforts to step outside comfort zones (Lather, 2006). Lather provides a good synopsis and critique for students to gain clarity on how the philosophy of qualitative research has developed, which in turn assists scholars of research to find their methodological niche.

As a researcher, there can be difficulties in being able to place oneself in the outwardly disarray of philosophical and sociopolitical evolution that forms research methodology. Intuitively I seek to understand how people understand their world, or what meaning people attach to their action as a human. This line of thinking fits best with the perspective of interpretivism. Interpretivism is one of the prevailing theoretical perspectives organising 'reality' and/or 'truth(s)' (Lather, 2006). Interpretivism is not as idiosyncratic as other paradigms that seek to emancipate (critical theory) or deconstruct (deconstructivist). Interpretivism is supported epistemically by constructivism, which in turn makes specific assumptions about our dynamic world. The following sections aim to make clearer the link between these two theoretical standpoints. How interpretivism supports this research is explained next, to clarify its importance as a theoretical perspective ontologically pertinent to this research.

### **3.3 Interpretivism**

About the mid-twentieth century there was a shift away from positivism as the dominant paradigm for thinking and research. The shift to give credibility to research about the human experience meant that theoretical perspectives such as interpretivism gained more respect in the wider domain of research (Denzin & Lincoln, 2005; Grant & Giddings, 2002). The main thrust of interpretivism in terms of research is to understand (as the researcher) the varied experiences people have and subsequent meaning that people garner from their experience. The emphasis is on 'varied' as experiences are indeed multifaceted and dissimilar, as much as they are similar. Hence an intricate process is entered upon where by the understanding(s) a person has of their experiences of illness is interpreted by the researcher, to construct further understanding in this case construct nursing knowledge. Therefore by using sensitive interpretation a further

sharpened understanding of illness is created; thus developing an understanding of being with illness.

### **3.3.1 Gadamer**

An essential contribution to the theoretical perspective of this research is the philosophical thinking and writing of German philosopher, Hans-Georg Gadamer (1900-2002). His work is the philosophical basis for Gadamerian hermeneutics (Annells, 1996; Phillips, 2007). The methodology of this doctoral research does not subscribe to hermeneutics per se, but many of the philosophical elements described by Gadamer sit comfortably with the theoretical perspective of this research.

The specific focus of Gadamer's thesis, *Truth and Method* (1960/1998), was to lay bare the phenomenon of understanding and to appropriately interpret how we understand, hence an accent on language. This is pivotal to this research. A further Gadamerian influence on this thesis is the belief that positivism misses 'other' and that being open to the world will elicit deeper understanding of experience. He writes: "the human sciences are connected to modes of experience that lie outside science: with the experiences of philosophy, of art, and of history itself" (Gadamer, 1960/1998, p. xxii). This same point is also true for this doctoral research, in seeking out human experiences I hope to reveal commonality and divergence, the layering of art and science. For this research, the human science of interpretivism with Gadamer's philosophy is what helps to illuminate the participant's experience of illness.

This research has conceptually used and included a number of concepts and ideas developed by Gadamer (Gadamer, 1960/1998): Bildung (openness to meaning)(1960/1998, p. 11), prejudice (questioning and reflecting) (1960/1998, p. 299), the whole (1960/1998, p. 291), understanding and interpretation and the fusion of horizons. The rest of this section is devoted to elucidating the essence of these five concepts and how they relate to this doctoral research.

#### **3.3.1.1 Bildung**

Gadamer (1960/1998) wrote: "All correct interpretation must be on guard against arbitrary fancies and the limitations imposed by imperceptible habits of thought, and it must direct its gaze "on the things themselves" (pp.266). For the interpreter to let themselves be guided by things themselves is not about a single conscientious decision-making, but is an evolving and iterative task. It is necessary to keep one's focus on the interpretive task throughout all the persistent interruptions that originate in the interpreter. Working out an appropriate synthesis

“by the things themselves, is the constant task of understanding” (Gadamer, 1960/1998, pp. 266-267).

In remaining open to ‘the thing themselves’ interviews need to be open to the participant as they speak and convey. The researcher waits in the silences, listens to the silence as much as the talk, listens to the language participants use, listens to what the language is, and listens to and for the extent of medicalisation and how a diagnosis has become personalised. In the process of personalisation, the researcher’s work is to reflect on the silence as much as the conversation and begin to construct an understanding of living with complex illness.

Bildung is relating to ‘other’ so as a researcher one remains open to common points of view or different points of view, in so doing uncouple one’s self from the familiar. Maintaining openness to meaning is crucial to exploring and understanding the experience of participants, if understanding and interpretation is to be achieved. In this research there are two ways Bildung is achieved: by maintaining a reflective account and by ensuring the second in-depth interview is participant driven (but still guided by the open questioning of the interviewer). The role of the reflective account is examined more closely in Section 5.5.1.

### **3.3.1.2 Prejudice**

Gadamer explains in order to gain understanding qualitative researchers need to recognise that prejudice is foreseeable. The prejudice he writes of is not a negative connotation, more that it may have a positive or negative worth (Gadamer, 1960/1998). Hence there is always “prejudices as conditions of understanding” (1960/1998, p. 277), understanding and the interpretation thereof do not exist without prejudice. Gadamer further implies “our understanding is always subject to revision when confronted with more convincing evidence and interpretation” (Grondin, 2002, p. 44) hence prejudice is that which is pre-understanding. Prejudice is expanded upon further in Section 3.3.3 which explains the influence of interpretivism together with the thinking of Gadamer on the research method.

### **3.3.1.3 The Whole**

Gadamer wrote about the concept ‘the whole’ throughout his book “Truth and Method”. The most exacting point he makes is “we must understand the whole in terms of the detail and the detail in terms of the whole” (1960/1998, p. 291). This points towards and links up with Bildung and prejudice, that as a researcher we need to stay open to meaning, that we try to make clear for ourselves our historical reality and that “full understanding can take place only within this

objective and subjective whole” (Gadamer, 1960/1998, p. 291). As a concept ‘the whole’ pervades this thesis, and will be encountered on numerous occasions in the chapters portraying the research findings.

### **3.3.1.4 Understanding and Interpretation**

Interpretivism is the ontological basis for this research, which emphasises there are multiple interpretations about life and living and therefore, there are multiple realities (Lather, 2006). As an extrapolation one would find this principle is applicable to the research context such that there are multiple meanings of the experience of illness. To come to know of this reality we understand and interpret wherein: “understanding and interpretation are ultimately the same thing” (Gadamer, 1960/1998, p. 388). This well known quote of Gadamer’s pertains to the study of hermeneutics and how the process of understanding is circular (Gadamer, 1960/1998; Phillips, 2007). Understanding is at all times about the language used to reveal an understanding (Dostal, 2002; Gadamer, 1960/1998, p. 463). Gadamer’s quotation earlier in this paragraph is most relevant to this research because the weaving of experience, interpretation, reinterpretation and an evolving understanding are constant in the interpretation by participant and researcher. The aim was to achieve the ontological goal of beginning to explain “what kind of being is the human being?” (Denzin & Lincoln, 2005, p. 22), which in this case was the human being with complex illness.

Gadamer quoted Kant: “Have the courage to make use of your own understanding” (1960/1998, p. 271). This point is gratifying in that it encourages new researchers to get on and do research. From understanding comes interpretation, hence Gadamer’s work helps detail what we as people do when we interpret in the world, particularly when we are not aware of doing this:

Even though in the following I shall demonstrate how much there is of *event* effective in all understanding, and how little the traditions in which we stand are weakened by modern historical consciousness, it is not my intention to make prescriptions for the sciences or the conduct of life, but to try to correct false thinking about what they are. (Gadamer, 1960/1998, p. xxiii)

Gadamer is clear that he is focussed on the philosophical thinking that explains the attention needed to understand and interpret, rather than develop a prescribed how-to-do method. Gadamer’s philosophy sits well with the chosen methodology for this research, interpretive description (Thorne, 2008). Thorne urges researchers to make clear their ontological and epistemic positions which must be in step with answering the research questions. One key question that this research is directed at is the experience and interpretation people have of illness. Interpretivism offers a theoretical position from which the research questions may be

explored rather than directly answered. Smythe and colleagues explain: “Our quest is therefore not to prove or disprove, not to provide irrefutable evidence but rather to provoke thinking towards the mystery of what ‘is’” (2008, p. 1391). As interpretive beings, researchers are not necessarily setting out to answer questions, but in some cases to pose more questions.

### **3.3.1.5 Fusion of horizons**

Gadamer views understanding as a process of dialogue, in this case between participant and researcher. The dialogue is a process of gradually coming to some level of concurrence about the issue discussed. During the dialogue where concurrence is established a common construction or ‘horizon’ is formed. Horizons shift according to our ever evolving understanding and interpretation. Gadamer’s concept of horizons relates to a progression that evolves, rather than something we progress to or aspire to. Our current understanding and interpretation are in our current world, and as our world expands our horizon moves with it. The fusion of horizons occurs as we understand our own horizon so that we can understand another. It is a “dialogic event of understanding . . . All understanding is practical” (Gadamer, 1960/1998, p. 3). “Understanding is always the fusion of these horizons supposedly existing by themselves” (Gadamer, 1960/1998, p. 306). The multiple realities are blended into a fusion of horizons should the participants in the dialogue (for this research the participant and the researcher) come to understand the matter in hand. This is an exciting prospect, indicating making meaning by coalescing interpretations, fusing and then constructing an understanding of illness.

These concepts from Gadamer’s writing are important to the theoretical perspective of this research. There is one additional theoretical notion that requires explanation in terms of how the findings of this research are expressed.

### **3.3.2 Merleau-Ponty**

Merleau-Ponty (1907-1961) was an important French philosopher; his work exploring the theoretical understanding of human perception. His argument was that the understanding of the body was as an object, according to the then current-day dictum of dualism. Like Gadamer Merleau-Ponty takes issue with the positivist concept of being, which “requires the subject free a clearing in the density of being” (1964/1968, p. lv). The positivists held that objectivity is not obtainable unless we separate or isolate the subject from being. Merleau-Ponty’s perspective was to “come to think the visible exhibited along the invisible dimensions, the levels, the pilings of the world: we discover a world in degrees, in distance, in depth, and in difference” (Merleau-

Ponty, 1964/1968, p. lv). Both Merleau-Ponty and Gadamer ask researchers to take on the maxim to explicate difference, provoke thinking toward difference, and that the subject is a being that should not be isolated into its parts.

One major thesis that Merleau-Ponty wrote of was the discerning of the visible and the invisible (Merleau-Ponty, 1964/1968). A particular concept that he dwelled upon is ‘The Flesh’, exemplary of Being<sup>1</sup>. The flesh is indicative of the sensible which in turn is what is visible. This idea of the visible is important to this research as participants are asked to verbalise what their experience was of illness, and it is a safe assumption that part of this conversation is of the body, the flesh, the sensible, the visible.

Merleau-Ponty wrote in May, 1960 “The sensible, the visible, must be for me the occasion to say what nothing is. . . Nothingness is nothing more (or less) than the invisible” (Merleau-Ponty, 1964/1968, p. 258). The afore quotation indicates how one can begin to ‘see’ what is there and with intellectual reflection what should or could be there. The notion of the in/visible is important to this research as it suggests that both aspects are important to consider, it importantly ensures some attempt is made to decipher the invisible.

### **3.3.3 The influence of interpretivism on research method**

Historically effected consciousness is an awareness of the history that sits behind understanding (Gadamer, 1960/1998). Understanding as a consequence of an individual’s own historical consciousness is a demanding assignment. It is unrealistic to be so impartial and self-reflective, to be detached from human interaction (Angen, 2000). Gadamer writes:

To think historically always involves mediating between those ideas and one’s own thinking. To try to escape from one’s own concepts in interpretation is not only impossible but manifestly absurd. To interpret means precisely to bring one’s own preconceptions into play so that the text’s meaning can really be made to speak for us. (1960/1998, p. 397)

Here Gadamer indicates we “belong to history” (Schwandt, 2007, p. 139). History is part of our being, and therefore also becomes part of how we operate as researchers.

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<sup>1</sup> Being: that which we are in the world.

Gadamer encourages researchers to stand back from our thinking or interpretive work, to recognise there will always be personal preconception and prejudice that influences our interpretation.

In this research, prejudice will always influence interpretation no matter who is interpreting. Staying with a Gadamerian perspective, prejudice requires self-reflection as a researcher and consideration as to how prejudice could influence interpretation and eventual understanding. Gadamer writes: “If we want to do justice to man’s finite, historical mode of being, it is necessary to fundamentally rehabilitate the concept of prejudice and acknowledge the fact that there are legitimate prejudices” (Gadamer, 1960/1998, p. 277). Prejudice is taken to have a positive meaning. Therefore as researchers Gadamer urges us to achieve understanding by recognising both the enabling and disabling prejudice that pervades methodology (Schwandt, 2007).

Some of the Gadamerian concepts such as prejudice, require us to stand back from our work as researchers and reflect upon what it is we do. Gadamer writes: “Reflection, as the capacity to take up certain distance towards oneself, is not the same as a relation of opposition to an object. Reflection is rather bought into play in such a way that it accompanies the lived performance of a task”(1993/1996, p. 53). Reflection allows us to consider how our own social constructions interface with the other being researched: “without construction, and without a constructing and constructed self, there is no meaning” (Alvesson & Sköldberg, 2009, p. 269). Meaning too comes from thoughtful reflection for: “neither is meaning lying around in nature waiting to be scooped up by the senses; rather it is constructed. ‘Constructed’ in this context, means produced in acts of interpretations” (Steedman, 1991, p. 54). Merleau-Ponty wrote “we see the things themselves. The world is what we see” (1964/1968, p. 3). What I see may differ from another, so reflection at best ensures the alchemy of data conceptualisation percolates through the theoretical perspective; hence for this doctoral study, a perspective of reaching an interpretation and understanding. Reflection is therefore a process integral to this research. Section 5.4.2 explains more detail about how reflection is used in this project.

This research did not set out to produce objective scientific concepts of one truth (Smythe, et al., 2008), more an interpretation of what participants told me as a researcher. Gadamer writes “language is the universal medium in which understanding occurs. Understanding occurs in the interpreting” (Gadamer, 1960/1998, p. 389); the interpretation allows understanding, to construct knowledge, in this case a construction of illness that is applicable to a clinical setting, from the data sourced. This issue is considered further in the next chapter in terms of how prejudice can be elucidated, in terms of the methodology for this research. The following section concentrates on how interpretation elicits particular understanding of illness.

### **3.3.4 Interpretivism as central to understanding illness**

Interpretivism allows research to dwell on the meaning of the topic of scholarly interest. To make meaning of illness and all that this conceptually encompasses, it is useful to turn to Gadamer again. He provides a helpful philosophical platform to consider the experience of illness as a dynamic equilibrium. He writes:

The recognition that something is lacking is connected with the idea of balance, and this means in particular with the idea of a restoration of equilibrium out of all the fluctuating conditions that constitute an individual's general state of health. Within this context illness represents a fall from self-sustaining equilibrium into a state of unbalance. (Gadamer, 1993/1996, p. 55)

Throughout the endless recorrecting of the body's equilibrium, there are times that one becomes ill. Gadamer explains how one may be unconcerned by the disequilibrium, a person denies the "truth of their own health" (Gadamer, 1993/1996, p. 55). Interpretivism directs researchers to listen to participants, to hear the participant's version of the truth of their own illness. The researcher may also hear what is not being discussed about the participant's ill health.

Understanding comes from being conscious of the self in the world as a whole, and that through a disruption of the whole one becomes conscious of evolving disequilibrium. Gadamer (1993/1996) writes that illness makes us acutely mindful of the disruptions of body, whereas in health we are less aware of our bodies, we are free of disruptions and therefore less attentive of health.

In summary, Gadamer has much to offer this research's theoretical platform, as ontologically our lives are experienced through interpretation and understanding. He provides essential points of focus: the researcher is predisposed to an historical consciousness which influences interpretation; the researcher brings an enabling prejudice to the activity of interpretation; and conventional methodologies may not necessarily fit research questions. Merleau-Ponty also offers the perspective the visible and the invisible to illuminate the experience of illness and thereby reveal the complex psychosocial structures that exist underpinning that experience.

A creative but careful intersect of theoretical perspective and methodology is required to progress the research question. For this research, interpretivism is central to explore the experience and interpretation people have of their illness. Added to this, with a Gadamerian lens, we distil the disequilibrium of illness as comorbidity (cardiovascular disease and high

blood glucose) and further come to recognise illness from Merleau-Ponty's perspective, by revealing the visible and the invisible nature of illness and health.

The following section links how knowledge is formed about the ill health that provides the context of this study. This section concerns itself with understanding how the ontology of this research is prerequisite to the epistemic aspect of this work.

### **3.4 Interpretivist Ontology and Constructivist Epistemology**

Constructivism and interpretivism are variously described in the literature (Crotty, 1998; Schwandt, 2001) separately; while Denzin and Lincoln (2005) make important points that consistently clarify how interpretivism and constructivism are linked. They write: "Qualitative research is endlessly creative and interpretive. The researcher does not just leave the field with mountains of empirical materials and then easily write up his or her findings. Qualitative interpretations are constructed" (2005, p. 26). This simple last sentence highlights the synergy between interpretivism and constructivism which relates to Section 2.8.1 of this thesis.

Part of a definition of knowledge for this research is offered in Section 2.8.1: that knowledge is more than the objective world. Indeed, knowledge is an outcome of human activity, that knowledge is a human construction (mental framework) (Guba, 1990) and this construction will include objective and subjective experiences. This particular research is in part interested in how participants construct their knowledge from their experiences of illness.

Interpretivism sets the scene for research to underpin what is understood as reality or truth as multiple realities (Alcoff, 2011). Constructivism epistemically supports interpretivism as an endeavour to construct knowledge about multiple realities. Denzin and Lincoln describe this as a relativist ontology (there are multiple realities) and subjectivist epistemology (researcher and participant co-create understandings), and is acted out in the natural world in terms of methodological procedures (2005, p. 24). This point of linking interpretivism and constructionism is a central tenet to this research. The methodology of this research relies on interpretation and any steps in synthesis that follow. Interpretation is constructed as understanding and further reconstructed as knowledge. This knowledge is then shaped so it is applied to the clinical setting, preferably from the place/setting that the data originated from.

A more in depth link to constructivism and how this theoretically relates to knowledge that evolves from this research is discussed in Section 3.5.

### 3.5 Constructivism

How knowledge is theoretically created has been debated for some time (Carter & Little, 2007; Crotty, 1998). Denzin and Lincoln (2005) and Guba (1990) demystify some of the confusion around this debate. Constructivism, a theory on knowledge development, is aimed at expressing how knowledge expands, at the individual's level (Denzin & Lincoln, 2005; Schwandt, 2001). It epistemologically acts as a precursor or trigger to the reasoning behind theoretical perspectives such as feminism or interpretivism (Denzin & Lincoln, 2005).

As a theory of knowledge, constructivism helps answer questions like: what is knowledge? and how do we acquire knowledge? As it is a subjectivist epistemology, the expectation is that people self-reflect (or perhaps they do not), and interact socially (or they may not) to generate meaning from experiences within tacit or physical environments. The emphasis here is on the individual i.e. how they interact independently and/or socially to co-construct meaning or co-create understanding.

Interpretivism rejects the idea that observation is neutral, that all knowing is perspectival knowing according to the individual, and for that reason open to multiple perspectives of interpretation (Angen, 2000; Harraway, 1988). Added to the notion of evolving knowledge through reinterpretation, Guba and Lincoln explain further that knowledge:

consists of those constructions about which there is relative consensus (or at least some movement towards consensus) among those competent (and in the case of more arcane material, trusted) to interpret the substance of the construction. Multiple 'knowledges' can coexist when equally competent (or trusted) interpreters disagree (Guba & Lincoln, 1994, p. 113).

Multiperspectival constructions of knowledge exist, developed through constant observation, interpretation of these observations, and reiteration of interpretation. At a more pragmatic level, in research, patients construct and reconstruct meaning as they learn from experiences. For the patient, knowledge is constantly evolving according to exposure to experience. As a researcher, I was interested in capturing the experiences of the knower (the participant or patient) so I could harness what I had heard, in order to understand and construct knowledge that is orientated toward the nursing discipline. Researchers construct and reconstruct knowledge according to their theoretical perspective. This research is situated in interpretivism, therefore as the researcher I engaged in a more active and reflexive reconstruction of knowledge. This was partly achieved by questioning and requestioning the participant during the interview process, or similarly the data during the time of analysis. There is a constant evolving refinement of what the data is telling the researcher. The researcher may share their reconstructions of knowledge

with participants. This is to identify if the researcher's interpretation and thus understanding is parallel to that of the participants'.

How does patient knowledge contribute to nursing knowledge? How does the patients' experience and interpretation of illness make a contribution to the nursing discipline? To help answer these questions, the next section covers how patient knowledge contributes to the greater knowledge base of health care.

### **3.5.1 Construction of patient knowledge**

The construction of a person's knowledge in part relies on experience (Paul & Elder, 2006). In the context of patient knowledge, Caron-Flinterman et al. state that experiential knowledge:

directly refers to the ultimate source of patient-specific knowledge – the often implicit lived experiences of individual patients with their bodies and their illnesses as well as with care and cure. Experiential knowledge arises when these experiences are converted, consciously or unconsciously, into a personal insight. (Caron-Flinterman, et al., 2005, p. 2576)

For patients, the interactions in clinical settings and outside these traditional clinical settings are all significant in the construction of their understanding as knowledge (Estabrooks et al., 2005; Henderson & Henderson, 2010). It is only more recently that patients' experiential knowledge is valued in terms of clinical research, and therefore, clinical knowledge (Caron-Flinterman, et al., 2005). However, epistemic discrimination has had to be overcome to realise the relevance, and importance, of patients' experiential knowledge. A discussion concerning this discrimination follows to position experiential knowledge of the patient further.

### **3.5.2 Discrimination of knowledge constructed by patients**

In the past some sources of knowledge have been devalued or thought of as unimportant to contribute to universal or academic knowledge usually because it is not considered a conventional source of academic information (Douché, 2007). This epistemic omission gives rise to epistemic discrimination, well described by midwives (Dalmiya & Alcott, 1993, p. 217) where midwives expert knowledge is not valued in the obstetric setting. Discrimination of nursing knowledge has been demonstrated (Benner, et al., 2009; P. G. Reed & Lawrence, 2008). Discrimination of nursing knowledge and patients' experiences have been devalued (Meleis & Im, 1999). To overcome epistemic discrimination of nursing knowledge, it is essential that

researchers value patient knowledge by building up research that is theoretically and clinically credible.

The heart of this research has been to reveal the experience and interpretation of a group of patients' illness, which in turn is interpreted, synthesised, and finally reconstructed as knowledge by the researcher. As a conscientious researcher I was aware of this shift of interpretation from the participant on to the researcher. Similarly I was aware of whose knowledge base was being accessed (the participants), in turn forming part of another's knowledge base (the researcher). This shifting of knowledge between parties in either direction is an important principle of this study. Its importance is because past research shows that human constructions of knowledge about illness are excellent sources to help health professionals develop a deeper understanding of the experience of illness (Coward, 2000).

The significance of researching interpretations of constructions of illness is that it reflects the patient's perspective. Contemporary nursing research values the viewpoint of the patient (Meleis & Im, 1999). The patient's construction of experience is useful for nurses to gain valuable insights into the complex worlds of patients with illness (Carel, 2008; Williams, 1984). By avoiding epistemic discrimination, research with patients facilitates a deeper understanding of how to support patients more effectively across clinical settings. How patients' experiential knowledge may act as a precursor to nursing knowledge is reviewed next.

### **3.5.3 Patient knowledge: Central to nursing knowledge**

Nursing knowledge has been expressed as patterns of knowing by nurse theorist Barbara Carper (1978). The patterns of knowing she described are: aesthetic, personal, ethical and empirical. The dimension of aesthetic knowing is of interest to this research as it has a focus on experiential knowledge, as the art of nursing: "this fluid and open approach to the understanding and application of the concept of art and esthetic meaning makes possible a wider consideration of conditions, situations and experiences in nursing that may properly be called esthetic" (Carper, 1978, p. 16). Carper asks nurses to develop nursing knowledge from all four patterns of knowing, that empirical knowledge alone is not the singular source of nursing knowledge.

Today emphasis is placed on aesthetic knowledge as it contributes to nursing knowledge (Estabrooks, et al., 2005). Aesthetic nursing knowledge comes from valuing patient experience (Henderson & Henderson, 2010), and also valuing interactions with patients (James, Andershed, Gustavsson, & Ternestedt, 2010) be it ever so trivial or unassuming. The experience of living with illness contributes to nursing knowledge in that it gives a balanced multifaceted view of the

world: the biomedical world of illness and the experiential world as constructed by the participant. How these aspects sit in terms of research in the clinical setting is discussed next.

### **3.6 Qualitative health research**

Medical research has placed great importance on quantitative process and outcomes, the most common translations being controlled trials, public health surveillance and epidemiological observation and synthesis. Miller and Crabtree describe this as clinical research functioning for “the dominant cultural tornado of global corporate capitalism” (2005, p. 607) with associated economic and political gain. Miller and Crabtree (1999) are both physicians and anthropologists. They have pushed for the inclusion of qualitative research within clinical research for some years with success. Yet there is always the overarching pressure of policymakers requiring more evidence based and outcomes driven research. A clinical practice setting is the contextual place and time where a ‘patient’ may find themselves interacting with health professionals. Quantitative research in the clinical setting usually concerns itself with access to health services, cost and best-practice. Increasingly there is recognition that access or cost alone cannot be addressed without the inclusion of the experience of attending clinical settings. Qualitative research in clinical settings can well attend to questions of this nature, so researchers can address both experiences and outcomes in practice.

Miller and Crabtree (2005) are supported by other researchers that label their work methodologically as clinical research (Grady & Edgerly, 2009). Furthermore, it has been suggested that qualitative research has spawned a sub-discipline, that of qualitative health research (Morse, 2010). This is supported by the publication of a text about qualitative methods in health research (Bourgeault, Dingwall, & de Vries, 2010). These authors agree that there is a specific sector within qualitative research that deals with clinical practice questions. What name it should have will no doubt unfold over time.

This doctoral research sits within qualitative health research. The chief reason for this is that qualitative health research places greater value on the theoretical drive behind the research (Giacomini, 2010). This too is an important point for the methodology of this research, interpretive description, which is detailed in the next chapter.

#### **3.6.1 Peculiarities of being a qualitative researcher in clinical settings**

Being a qualitative researcher has some interesting peculiarities. It requires that the inquirer becomes involved, even becomes a source of information (Holloway & Biley, 2011). Upon

reflection this holds true for those working in clinical settings too. Holloway and Biley provide a good summary of what qualitative research could involve. There are two issues worth examining in more detail for those researching in clinical settings, using qualitative methodologies. One issue concerns insider and outsiders in research, and a second issue is how one works with vulnerable patients as participants.

The person conducting qualitative research is often an insider (Holloway & Biley, 2011), a health professional familiar with the research environment (Morse, 2010; Thorne, 2008). They usually ask research questions that stem from the bedside, from clinical observation of patients. On a positive note, the 'insider' knows the social mores of the chosen clinical environment, knows the work within specialised clinical settings (e.g. infectious isolation), can assess whether patient status is optimal in relation to judicious data collection, is likely to cope with distressing situations that may transpire, and is comfortable with the physical nature of sights sounds and smells that may occur during the research (Morse, 2010). Insider' researchers are potentially somewhat hardened to the complexity of the clinical environment so may inadvertently miss, or trivialise important research development opportunities in terms of questioning, data collection and analysis. It is, therefore, important the researcher is sufficiently reflective to recognise and work with these possibilities. The need for a naïve perspective is a significant consideration in qualitative research, and more so in qualitative health research addressing sensitive questions in clinical settings (Miller & Crabtree, 2005; Morse, 2010).

Holloway and Biley (2011) explain that the qualitative researcher needs to be able to grasp both the insider and outsider perspective, as personal experiences and knowledge become conduits to explore and interpret data. This is especially so at the level of interpretation and understanding for this doctoral research. The issue of insider outsider research has also been addressed by Dwyer and Buckle (2009); it being a dichotomy which researchers should be astute to and yet remain flexible to the likelihood that researchers are both insiders and outsiders at any one time.

For this research it is acknowledged that I am mainly an insider, having worked with people with complex illness in hospital settings (refer also to Section 1.1.3). However I also know I have not been a patient with complex illness. In keeping with points made about a naïve perspective, it will be important to reflect upon issues that may distort interpretation and understanding, this distortion being addressed later in Chapter 5.

The second issue raised is that of working with participants as vulnerable patients. Goodin (1985) provides an excellent social critique of the vulnerable in our communities, developing the idea of social responsibility to vulnerable people. Liamputtong (2007) writes of our ethical responsibility to be mindful of how we work with vulnerable people. At a clinical level it is

thought to be easier to view all patients as vulnerable until found otherwise (Nicholson, 2002). This research holds to this debate as the participants in this study were physically at their lowest, and mentally often exhausted due to their physicality. For this research, the ethics committee approved a process whereby a third party asked patients to become involved in the research, not the researcher. This process worked well as long as the third party was well informed of the research aims, and the patient was seen to be uncoerced.

### **3.7 Conclusion**

In conclusion this chapter has addressed a number of theoretical perspectives and concepts that directly relate to this study. Interpretivism is a theoretical perspective acknowledging that people have varied life experiences and will interpret these experiences according to historical and social context. Constructivism epistemologically supports interpretivism. This perspective indicates that people generate knowledge and meaning from their interactions and experiences in the world, that meaning is constructed. The synergy of interpretivism and constructivism theoretically underpins interpretation of experience as constructed by the participant. The participant's experiential knowledge as a patient is then reconstructed, interpreted and finally synthesised by the researcher. This is contextually synthesised as nursing knowledge to give clinicians greater insights, in this research insights into how patients live with complex illness.

This chapter has also examined how Gadamer influences the principles of interpreting and understanding. The language of Gadamer is used to express how constructed knowledge makes a contribution to nursing knowledge through research in clinical settings. This theoretical perspective sits well with the methodology of this research, interpretive description. How interpretive description permits a process of (re)interpretation of reality and construction of clinical knowledge is examined in the next chapter. The above discussion has also touched upon the development of qualitative health research, and how this could relate to this project.

## **Chapter 4**

### **Research methodology: Interpretive description**

#### **4.1 Introduction**

This research seeks to answer a clinically-derived research question; therefore, this should also be reflected in the research methodology. Interpretive description is the methodology driving this research, a methodology supported by interpretivism wherein interpretation (by both participant and researcher), plus making meaning of clinical phenomena are pivotal. This chapter briefly reviews the origins of interpretive description (Section 4.2). Then follows an exploration of how the theoretical perspective of this research sits with interpretive description (Section 4.3). Interviewing is an essential form of data collection for interpretive description (but not the only method of choice), and is considered in some detail as it is the method used for data collection for this project (Section 4.4). Finally, interpretive description evaluation criteria are presented (Section 4.5) followed by an explanation of how Thorne's evaluation criteria were managed in this research.

#### **4.2 Origins: interpretive description**

Nursing scholars have long used qualitative research methodologies, which find their origins in other disciplines (sociology and anthropology in particular), but were applied to clinical practice questions. Over 20 years ago Morse wrote how qualitative researchers embark on valid qualitative research however "there is no label for this type of research" (1991, p. 18). At this time traditional research theory and methodology (e.g. phenomenology, ethnography and grounded theory) were often commandeered to research designs aimed at answering research questions by nurses. Repeatedly it was found that there was a mismatch between theory and research question. Subsequently research design departed from, or was disparate to, the research question and the manner data were analysed and presented (Thorne, Kirkham, & MacDonald-Emes, 1997). Since the late 1990s there was some interest to develop a methodology that suited research questions from clinical settings. Interpretive description advanced by Thorne and colleagues, is one such development of methodology to suit the intricacies of qualitative clinically-based research (Thorne, 2008; Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). It is described in the literature as applied interpretation (St George, 2010), wherein human social experiences are studied "within a nondualistic philosophical tradition" (Thorne, 2008, p. 48).

About the same time, Sandelowski (2000) another nurse scholar, advanced her ideas concerning qualitative description. Sandelowski (2010) wrote a paper to emphasise the need for interpretation of qualitative information, that data cannot be left in limbo without synthesis and theoretical organisation. Sandelowski was also at pains to emphasise that research methodologies are evolving and health researchers should avoid rigid classifications of these methodologies. It seems that Sandelowski is on the same research path as Thorne, as evidenced by Sandelowski's congratulatory foreword to Thorne's (2008) book.

Thorne has detailed a "methodological ancestry" (2008, pp. 26-33) to determine the genesis of interpretive description. This ancestry is largely related to naturalistic inquiry (Lincoln & Guba, 1985). This means the research focus is of "human action in some setting that is not contrived, manipulated, or artificially fashioned by the inquirer" (Schwandt, 2001, p. 174). Naturalistic inquiry is methodologically related to interpretivism. Interpretivism ontologically relies on methods primary to naturalism to reveal the multiple faces of reality, taking care not to efface the distinctions between these two theoretical standpoints. This ensures that contextually, daily life and its complexity is not lost in collecting and synthesising data. This places the clinical setting at the forefront in terms of interpretive description.

### **4.3 Synergy: Theoretical perspective with interpretive description**

Interpretive description arose from a perceived lack of methodological options that could answer research questions based in clinical settings. Sally Thorne, a nurse academic and researcher, worked with a team of colleagues to develop this methodological approach to fill a gap in methodological rigor identified in qualitative health research (Morse, 1991; Thorne, et al., 1997). Interpretive description is epistemologically pragmatic, informed by practice (Giacomini, 2010). It is a methodology resting comfortably with the epistemological theory of constructing knowledge, particularly considering questions from clinical settings. This is because clinical settings are dynamic, hence research in such settings should be encouraged to evolve accordingly.

This chapter is based on Thorne's work (Thorne, 2008; Thorne, et al., 1997; Thorne, Reimer Kirkham, et al., 2004), explaining how interpretive description developed and why this methodology has been chosen over others for this doctoral research. The theoretical perspectives of interpretivism and constructivism provide a theoretical frame for the methodological operations of interpretive description. The researcher is an interpreter, preoccupied with making meaning, which is harnessed as understanding of clinical phenomena, simultaneously constructing knowledge, from understanding gleaned from interpretation. Knowledge is constructed within a clinical context (those with cardiovascular disease and

prediabetes), because participants interpret their health predicament (Jonsdottir, et al., 2004), as does the researcher. All is a dynamic and evolving process to come to a meaning of the clinical phenomenon of interest, complex illness.

#### **4.3.1 Constant interpretation**

A central notion of Gadamer's philosophical thinking is that "interpretation is always on the way" (Annells, 1996, p. 707), hence interpretation is a constant. This sits well with the dynamic clinical environments in which this research is based, a hospital cardiac care unit and outpatient departments. This constant seeking for new interpretation maintains an open door for the development of new meaning, and therefore further construction of knowledge, about living with complex illness. This openness is also sensed (but not directly stated) in interpretive description. Interpretation is not about objective phenomenon per se, more the social construct as experienced by a person, as a subjective being (Thorne, 2008). Smythe et al. add that relevance can be lost when context is cut short: " 'showing' requires that the pause button be pushed to allow us to see a still frame of being before the play button once again activates that which in the living can never be stopped" (2008, p. 1390). That which "can never be stopped" (i.e. living) is indicative of the need to continually interpret and understand; interpretive description would stipulate emphasis on context, i.e. research-based theorising reaching back into clinical settings.

#### **4.3.2 Co-construction as method or ontology?**

Thorne (2008) insists that research should have a clear theoretical perspective to drive the research. Interpretivism as the principal ontological driver of this research, which posits that there are multiple realities according to the interpreter, hence there is no one reality (see Sections 3.3.1.5 and 3.4). Understanding about this reality (of the participant) may come about due to 'co-construction' (or co-creation). Clarification is required here to explain how this co-construction occurs. Is co-construction a procedural entity i.e. a method where in the participant and interviewer physically work together to develop and synthesise the study data? Or is co-construction related to how reality is interpreted by the participant, and then later in a different frame, reinterpreted by the researcher? The former is a negotiated difference in interpretation, the latter allows for difference in interpretation, allowing for multiple understandings of reality (hence sits better with interpretivism). This research has ontologically co-constructed understanding about complex illness. This is an important issue to labour because the difference in interpretation between participant and researcher may be considerable. In the methods chapter that follows there is a discussion concerning how this potential problem is averted.

### **4.3.3 Meaning making in interpretive description**

Schwandt writes about ‘meaning’ in qualitative research as: “a taken-for-granted assumption in qualitative inquiry is that it studies meaningful social action” (2007, p. 185). This indicates that qualitative work is designed to work beyond description and interpretation. The work is about thoughtful meaning placed on interpretation, posing questions such as “what could this all mean?” just when meaning seems to become clearer. Thorne encourages the researcher to study meaningful social action in clinical settings, to always strive further in our interpretations of clinical phenomena, further than we had hoped or intended. A definition allows further clarification:

Interpretive description is a qualitative research approach that requires an integrity of purpose deriving from two sources: (1) an actual practice goal, and (2) an understanding of what we do and don’t know on the basis of the available empirical evidence (from all sources). It constitutes a method that generates questions from that grounding, pushes one into the “field” in a logical, systematic and defensible manner, and creates the context in which engagement with data extends the interpretive mind beyond the self-evident . . . to see what else might be there. (Thorne, 2008, p. 35)

This large quote tells us as researchers to be bold in how we approach clinical questions, and be creative in how we construct knowledge from understanding and making meaning of clinical phenomena. Thorne is clear that researchers remain in command of creativity by remaining logical, systematic and can justify what the method of research is. As an example, interpretive description borrows methodologically from other traditional methodologies. She also encourages the use of multiple data sources to help elucidate the phenomenon studied, which a traditional methodology such as phenomenology may not usually promote.

#### **4.3.3.1 Understanding**

Understanding and interpretation are interconnected to the point of being indistinguishable according to Gadamer (1960/1998). There seems to be a constant restlessness of the intellect to seek understanding through interpretation, a process which is never definitively complete. Interpretive description methodologically requests the researcher to stay close to the clinical setting, in order to reach points of understanding. To achieve this, nursing research too becomes a labour of interpretation and contributes to understanding as “formal evidence . . . shared clinical wisdom, pattern recognition, established practice, ethical knowledge and the ‘how to’ of

competent practical application” (Thorne, 2008, p. 26). This is also the work of this doctoral thesis, with particular emphasis on application of research findings back to the clinical setting.

Nurses in clinical settings also undertake praxis, a reflective form of interpretation and understanding, which is recycled back to the practice setting. It is this applied value that interpretive description aims to harness in the context of research. Thorne writes: “Nursing’s comfort within the world of complexity and contradiction, its enthusiasm for ways of thinking that acknowledge the messiness of the everyday practice world” which extrapolates back to nurse researchers’ considerable involvement in applied qualitative clinical research. We could further perceive that Gadamerian understanding underpins understanding in applied qualitative clinical research.

#### **4.3.3.2 Understanding with prejudice**

Gadamer writes of our need to recognise self in our work, avoiding any attempt at bracketing (suspend judgement about existence in the world), avoid working with phenomena in isolation (Schwandt, 2007, p. 24). Gadamer strongly disagreed with bracketing, expressing how it may be advantageous to have a prejudice (in a positive sense). Taylor (2002) explains prejudice from a Gadamerian perspective:

If our own tacit sense of the human condition can block our understanding of others, and yet we cannot neutralize it at the outset, then how can we come to know others? Are we utterly imprisoned in our unreflecting outlook?. The road to understanding others passes through the patient identification and undoing of those facets of our implicit understanding that distort the reality of the other (p. 285).

If we as researchers recognise our own bias, this relieves some of the risk of potential misinterpretation and gives weight to the ‘taken-for-granted’ information that may otherwise be overlooked during data collection and analysis. Thorne writes how purist interpretive traditions such as phenomenology have zeroed in on research that reveals “deeper essential structures of ‘being’” (2008, p. 31). This does not exclude interpretive description from deep understanding but rather keeps the researcher firmly (and deeply) in the real world of clinical settings and all that this entails.

#### **4.3.3.3 Description**

Description indicates an explanation of what it is that one observed (Sandelowski, 2000). Thorne (2008) explains how description is often inadvertently extended into explanation. A

further observation has been made that clinicians constantly perceive but also make sense of these perceptions by providing examples of application (St George, 2010). This is the nub of Thorne's thesis, to maintain theoretical integrity but work hard on interpretive authority. It matters not if description is extended to interpretation, what does matter is that credibility needs constant defining in terms of process and outcome (Denzin & Lincoln, 2005), to avoid "epistemological confusion" (Thorne, 2008, p. 221).

#### **4.3.3.4 Inductive analysis**

The methodological approach to data analysis is inductive and seeks "understanding of clinical phenomena that illuminate their characteristics, patterns and structure . . ." (Thorne, Reimer Kirkham, et al., 2004, p. 6) which works mutually with data collection. Hence as data are collected there are periods of reflection that allow the researcher to make some preliminary analysis before collection continues. Thorne persuades the researcher to be thoughtful and analytical, to shift beyond an intuitive analysis to a carefully constructed and crafted analysis. Hence analysis is an intellectual process, it does not subscribe to an exact formula but does demand a logical intellectual process that directs the research to meaningful findings (Thorne, 2008).

#### **4.3.3.5 Applied nature of interpretive description**

This methodology's main strength is its intent to theoretically underpin qualitative research that answers clinical questions (Carlander, Ternestedt, Sahlberg-Blom, Hellström, & Sandberg, 2011; Maheu & Thorne, 2008; St George, 2010; Thorne, Con, McGuinness, McPherson, & Harris, 2004), hence research findings are applied back to the clinical setting. Nurse researchers respond to the need of evidence-based practice by providing the evidence (Aveyard & Sharp, 2009). Interpretive description as proposed by Thorne (2008) is well placed to answer questions that require an eye on the experience of illness because that is what it was specifically developed for. It is not so much aimed at developing evidence for theoretical questions; it centers activities on answering clinical questions, and how research findings can be applied back into practice settings.

Once data are collected and analysed, a process of making sense of findings follows. Thorne explains on a theoretical level how researchers can engage with the data at a level to shift beyond description:

The intricate process of sense-making can begin early and continue throughout data collection and analysis . . . In the conceptual process, you become acutely aware of the

important elements within your data set, the meta-messages that the final set of findings must convey . . . (Thorne, 2008, p. 165)

Thorne describes how making sense of the data begins the minute it is heard, and is an ongoing process. The researcher becomes intensely aware of recurring threads of information during the time of sense-making. This may begin as a description of the clinical phenomenon, gradually introducing an element of interpretation as the meta-messages unfold conceptually.

The following sections look at two further aspects of the research that are important to the process and outcome of interpretive description: the interview and the concept of research credibility. Thorne (2008) conveys significant points about both aspects in terms of interpretive description as they are central to other qualitative methodologies. The interview is the forum in which the experience of illness is constructed, and is considered next.

#### **4.4 Interviewing for interpretive description**

There are many excellent sources available that address the detail of how an interview should proceed and how the interviewer should conduct themselves (Fontana & Frey, 2005; Fontana & Prokos, 2007; Holloway & Wheeler, 2010; Minichiello, Aroni, Timewell, & Alexander, 1995; Patton, 1990; Spradley, 1979). The interview and the interviewer in terms of interpretive description are explored next, and in turn related to this doctoral research.

##### **4.4.1 The interview**

The interview provides a forum for participants to recount their experiences in a natural unpremeditated manner. The open-ended questions requisite for this research allow participants to reflect on their experience and build the interview (answering questions, or free-talk) around their interpretation. This sits well with the theoretical framework for this research of interpretivism-constructivism, in that participants answer questions according to their contextualised history, constructing and reconstructing their experiences as a particular understanding.

Interviewing people has the potential to assume that all that is said is their reality be it embellished or distorted or not. Hence there is a suggestion that perhaps nurse researchers have relied excessively on the interview to reveal experience (Benner, et al., 2009), in part because the interview is incorrectly described as deceptively simple (Kvale, 1996). The argument goes further to suggest that this approach has exposed more about empathy, and less about knowing

in the existential sense (Thorne, 2008). These were points worth considering for this research. It would not be constructive to focus solely on the subjective reactions participants have of their dramatic emergency admission to hospital. The research should (and did) focus on how people experience illness (hence potentially the subjective experience) but also asked participants why they recounted specific incidents as an entrée to their interpretation of what took place. The interview is a forum in which the researcher begins with a question and upon answering the participant is constructing the experience in a context, which lends itself to interpretation first by the participant and then later by the researcher as a separate line of analysis. Interpretation by the participant is concerned with directing scrutiny inward, while interpretation by the interviewer is about directing scrutiny outward to make sense of living in the world of illness.

#### **4.4.2 The interviewer**

There is evidence in the literature (Miczo, 2003) that the roles of researcher and participant are not necessarily mutual, the participant has a marginalised status, even in qualitative research. Thorne (2011) vigorously supports the participant role suggesting the researcher makes concerted efforts to ethically provide a mutual and safe forum for participants to express themselves. Thorne's main reason for this is because she believes nurses need to understand the experiences of patients in a way that allows research application "to the diversity of context and complexity within the actual real time setting, and not because they exemplify something that is theoretically interesting". This point highlights how the interview is a central tool of the research process.

Critique of the standard interview describes objectivity as nigh impossible (Miczo, 2003), and Thorne (2008) supports this point too. Thorne writes that no matter how diligent a researcher is, we should always detail our professional history both to the participant and when reporting research. As possible, the interviewer is an active participant (Lowes & Prowse, 2001), in the interview encouraging the participant to make some meaning out of their experiences. The interviewer considers the participants answers, asks further questions and begins to reconstruct the elements of the interview for clarification. This ultimately should develop a depth of understanding of the essential issues for the participant (not the researcher).

As stated earlier, the researcher does not come to the work of the interview without considerable forethought about matters such as: building rapport, being creative in questioning, recognizing inconsistency, consciously working forward in questioning and reiteration (Spradley, 1979). Thorne (2008, chapter 6 specifically) writes about similar points but not exclusively about the role of an interviewer, more the role of the researcher. Therefore, the points she makes are transferable to various roles: interviewer, observer, or analyst. The detail concentrates on:

tracking reflection, learning not to lead, disclosing professional position, stepping out of role, working through informed consent, and constraining your influence as possible.

One particular point worth drawing out is that interviewing tends not to lead participants with a line of closed questioning (Thorne, 2008). Interviewing requires the researcher to leave behind their role as clinician as soon as the interviewer's role is assumed. As an interviewer there is a need to be open to the participant, to learn from the participant, and help the participant realise that they are the teacher (Spradley, 1979). As nurses it can be easy to assume that we are capable interviewers. We may be accomplished at extracting clinical information, but this does not directly translate to good interviewing for research. As researchers our questioning is required to be more open-ended with perceptive listening and reflection, and questioning which is not always spontaneous in the role of a clinician. Thorne (2008) writes of occasions when the interview becomes more a clinical circumstance which requires the researcher to revert to the clinician role, dependent on the emergent situation or crisis.

It is helpful to keep some degree of focus during the interview by using an interview schedule of some description, keeping a focus on a line of research questioning as opposed to a line of clinical questioning. Where possible the researcher needs to maintain a balance of focussed questioning and yet allow for spontaneity as it is this very point of dialogue aberration that may serendipitously become useful unforeseen qualitative information (Hutchinson, Marsiglio, & Cohan, 2002; Spradley, 1979). Thorne aptly writes about the production of quality data, that it: "will derive from a carefully thought out frame of reference, attitude, and communication style designed to build rapport (without stepping over the boundaries into friendship or therapy!)" (2008, p. 129).

A further issue to be considered is the use of evaluation criteria for research positioned in interpretive description. The following section is organised to present how evaluation can improve the honesty with which a researcher self-critiques their work to demonstrate research credibility. Credibility is enhanced by a construction of self-critique within the evaluative framework of interpretive description. By reflecting on the research process, the evaluation illuminates any misconception of understanding and synthesis, particularly if points of process are not logical or overt.

#### **4.5 Evaluation criteria for an interpretive description**

Qualitative researchers have long debated and more recently described evaluation criteria that should ultimately be met by any qualitative research to demonstrate the quality of such a project (Caelli, Ray, & Mill, 2003; Melia, 2010; Thorne, 2008) or specifically levels of validity (Angen,

2000; Whittemore, Chase, & Mandle, 2001). The main aspects seen to be most indicative of quality research are: “noting the researchers’ position, distinguishing method and methodology, making explicit the approach to rigor, and identifying the researchers’ analytic lens” (Caelli, et al., 2003, p. 1). For qualitative research to be judged rigorous and meaningful, Thorne describes the following evaluation criteria: epistemological integrity, representative credibility, analytical logic, interpretive authority (2008, pp. 223-226). These criteria are considered in view of this doctoral research.

#### **4.5.1 Epistemological integrity**

All qualitative research should exhibit “epistemological integrity in the sense that there is a defensible line of reasoning from the assumptions made about the nature of knowledge through to the methodological rules by which decisions about the research process are explained” (Thorne, 2008, pp. 223-224). There should be clear links between epistemology, the type of research question asked, methodological preferences for data collection, interpretation and strategies that enhance the research dissemination. For this research the epistemological position has been presented in the previous chapter; that knowledge is constructed by understanding human experiences and subsequent interpretation of these experiences. How knowledge is constructed both by the participant and later by the researcher forms part of the research findings.

#### **4.5.2 Representative credibility**

Thorne (2008) introduces a credibility issue relating to sampling within qualitative research. The central issue is that sampling should be aligned to the theoretical perspective and methodological position of the study. As a researcher, I have embraced a strong interpretivist-constructivist approach, which calls for a sample sufficiently large to demonstrate recurrent themes from interview data, and yet remain open to the data for new themes, new constructions of knowledge concerning people’s experience of illness.

There should also be some thematic matching found in both the research interview data and the literature. Greater credibility is afforded if “maximal variation” is achieved before claims of conceptualisation are made (Glaser & Strauss, 1966). A further point of representative credibility is achieved as participants are interviewed twice in this research. This allows the interviewer to verify any contradiction or agreement in the first interview, i.e. there is an opportunity to reopen a line of questioning and reconstructing. This is particularly true for interview data that seems out of step with themes already identified. Clarification of ‘other’ or

contradiction is an important finding for potential interpretation of data. Interpretivism encourages the examination of 'other', and in complex illness the tailoring of health care to the individuals needs may be the difference between success and mediocre service delivery.

### **4.5.3 Analytic logic**

There is an expectation that an analytical process is made evident in the reporting of all qualitative research which goes beyond the common stipulation that 'inductive reasoning' is used throughout the research (Miles & Huberman, 1994; Thorne, Reimer Kirkham, et al., 2004). Qualitative researchers complain that there is a lack of process reported in qualitative research literature (Caelli, et al., 2003; Thorne, 2008). An audit trail should be maintained so the progression of the research process is clear. During this research I have maintained a reflective account serving as a starting point to explain the research process. These notes provided a starting point for reasoning, justifying why particular steps were taken in terms of method and analysis. It is important to use the reflective account to explain how the analysis progressed, and how further interpretation allowed findings to emerge. The literature concurs with the need to maintaining an audit trail (Schwandt, 2001) of "an explicit reasoning pathway along which another researcher could presumably follow" (Thorne, 2008, p. 225).

### **4.5.4 Interpretive authority**

The aim of this research is to provide an explanation of how people experience and interpret illness. Interpretive authority requires that this interpretation is trustworthy and demonstrates some truth beyond the biases of the researcher (Thorne, 2008; Thorne, Reimer Kirkham, et al., 2004). For the research reported here, the intention is to offer a coherent scholarly representation of the phenomenon under scrutiny; as a representation of data as an interpretive explanation. The explanation concentrates on both the shared trajectory of illness and the experiential deviations (Kearney, 2001), with subsequent careful extrapolation to conceptualisation of findings. This means avoiding over-interpretation wherein the data set clearly does not match the interpretation made by the researcher.

At approximately the same time that Thorne et al. (2004) were developing criteria toward the credibility of qualitative research, Sandelowski and Barroso (2003) described a typology of qualitative findings. Their typology refers to interpretive explanation as the most processed qualitative data i.e. interpretation that can potentially be somewhat removed from the original data. This research aims to examine qualitative data in juxtaposition to the participant's context and should be immediately recognizable in the context of clinical practice. Interpretive

authority (Thorne, 2008) demands that the researcher should check their knowledge construction with the participants, otherwise referred to as “validity-as-reflexive-accounting” (Altheide & Johnson, 1994).

A useful summing up on this issue is provided by Benner (1994). Benner explains that interpretation “must offer increased understanding, and must articulate the practices, meanings, concerns, and practical knowledge of the world it interprets. . . One must not read into the text what is not there” (1994, p. xvii). Here her emphasis is on honest thoughtful interpretation which is the aim of this research, where interpretation constructively extends or challenges current nursing knowledge about the experiences of people with complex illness.

These criteria call into question the worth of posing the research question. The purpose of having knowledge about peoples’ experience and interpretation of their illness is to identify a construct of illness from the participants’ perspective. This perspective of experience and interpretation is not clearly found in the research literature. A further purpose is to use this constructed meaning to support improved patient care.

#### **4.6 Conclusion**

The synergy of interpretivism-constructivism heralds constructed knowledge (new, old and understood) through interpretation and understanding of experience. Knowledge is constructed by the participant; which is in turn interpreted, reconstructed and reconceptualised by the researcher, to develop nursing knowledge that is directly applicable to nursing practice, the context being complex illness. The methodology of this research aims to reveal the experiences of participants as they are hospitalised for an acute condition as illness. The philosophical perspective of interpretivism-constructivism provides a frame to interpret and understand the meaning people give to experiencing life with illness. This chapter has also highlighted particular elements of interpretive description that attend to research credibility and auditing of process. The following chapter presents detail of the research method used for collection, analysis and interpretation in this study

## **Chapter 5**

### **Methods**

#### **5.1 Introduction**

The purpose of this study was to establish the experiences and interpretation people have of illness, hence it was essential that people with illness were able to convey their experiences and interpretation with some ease. Interviews were the primary procedure employed to allow participants to express their thoughts, feelings, and views and was a way to elicit how participants progressed in their recovery. The experiences of the 33 participants for this study and their interpretation of their illness (ACS and hyperglycaemia) were examined when they were originally in hospital and about nine months later (29 participants) after discharge.

The process and methods enacted for this research study are outlined in this chapter. Section 5.3 briefly introduces the cohort for this study, Section 5.4 covers the ethical considerations for the research, Section 5.5 details the interview process and Sections 5.6 and 5.7 discuss in detail how the interview data were analysed and interpreted respectively.

#### **5.2 The researcher's expertise**

In Section 1.1.3 I mentioned my role as a nurse researcher managing clinical trials for new antihypertensive medication. This role involved liaison with health professions, recruitment of participants, developing ethics applications, collecting all data for one large multi-national study, data entry, and trouble-shooting issues as they arose. One of my principal roles was to maintain good communication with participants.

During the development of my Master of Nursing I was responsible for the research design and execution. One main point of learning was to see the process of research to its end point; completing my thesis and publishing results. A further point of learning was the ability to facilitate a research interview. My supervisor at the time and I together developed my expertise for interviewing research participants, making the distinction away from interviewing patients in clinical settings. Learning to actively listen was also important to becoming a researcher. These learning experiences helped to build skills also necessary to undertake this doctoral study.

### **5.3 Participants**

The participants were recruited at the Heart and Lung Unit of a regional hospital, the same participant group for the RICE study (Section 1.5). The criteria for inclusion in the study were that they had experienced an acute coronary syndrome or elective cardiac procedure and had accompanying hyperglycaemia (HbA1c > 42 mmol/mol or fasting plasma glucose  $\geq$  6.1 mmol/L). Baseline characteristics and socio-demographic factors of the recruited participants are presented in Tables 1.3 and 1.5 (Section 1.5) and the biochemical and physiological parameters at admission and nine months after discharge are in Table 1.4 (Section 1.5).

Seventy five percent of the cohort were male and the average age of the participants was 63 years (Table 1.3). Many participants were in hospital or still off work for interview 1; however, the majority of participants who could, had returned to work by the time interview 2 was conducted (Table 1.5).

### **5.4 Ethical considerations**

Ethics approval for the HRC/DHB translational research (Section 1.6), which this PhD study was part of, was given by the Health and Disability Ethics Committee, Central Regional Ethics Committee in August 2009 (CEN/09/04/019, Appendix 2). The main ethical elements to address in relation to the doctoral study were informed consent, confidentiality and protecting specific rights of participants, making sure the potential benefits and harm are transparent, and an assurance that knowledge production would be disseminated appropriately (Holloway & Wheeler, 2010; Jackson & Borbasi, 2008).

Foreseeable ethical issues in analysis are related to the theoretical frame from which this research is directed. Interpretivism has emphasis upon multiple realities added to which the researcher as interpreter will produce an analysis which is potentially a “non-systematic approach” (Miles & Huberman, 1994, p. 289). This comment refers to the need for the researcher to remain astute to potential ethical issues and work with research supervisors to prevent challenging situations occurring where possible.

#### **5.4.1 Insider and outsider considerations**

In Section 3.6.1 consideration has been given to how the researcher grapples with being an insider and outsider. For the purposes of this research I identify mainly as an insider and a particular incident highlights this. The clinical staff on the unit where recruitment occurred were supportive of the prospective research. There were a number of older staff I had worked with

previously in clinical settings so this made initial introductions easier. However I clarified at the outset that I was on the unit as a researcher, not as a clinician and this difference in role was respected. This distinction of roles was also made when meeting potential participants, clarifying that our interactions would be at a research level. Also, if clinical questions were asked by participants during interviews I always referred them directly to their nurse managing their care that shift as it was important to not blur the role as researcher with that of clinician.

#### **5.4.2 Informed consent and confidentiality**

Potential participants were initially offered verbal information followed by written information: introductory letter (Appendix 3), information sheet (Appendix 4) and consent form (Appendix 5). The information sheet made available to the potential participant, outlined the research aims and the role of the researcher and how researchers could be contacted if participants had questions. Once the consent form was signed the participant was considered available for their first interview.

Confidentiality of the interviews was achieved by removing names from interview transcripts and giving transcripts a coded name (cryptic initials, participant number, interview number, date of interview: CKS19, int1, 12Aug10). Pseudonyms were not used, only initials were used. The code book was kept separate to all other research data in a locked cabinet in the researcher's office. All interview data was accessible to myself only. Validation of themes involved sharing sections of interviews with my supervisors.

#### **5.4.3 Privacy**

To minimise harm to the participant plus ensure justice wherein the participant is treated with respect, adhering to the principles of privacy and confidentiality was essential (Roberts, 1998). Section 5.4.2 has detail concerning how confidentiality was managed within this study.

Privacy comprised various levels: the sensitivity of information to be gathered, the setting that information is gathered from, and dissemination of results. The sensitivity of information gathered throughout interviewing was considerable so it was important to ensure that participants were comfortable about answering questions with the option of not answering questions. Participants generally were very happy to answer what may be considered private questions. For the first interview people were in hospital, so a private room was sought to undertake interviewing. Some participants were tired and remained on their beds but were still

keen to participate. These participants were shifted on their bed into a private room to be interviewed.

On one occasion a private interview room was not available for a participant to be interviewed. Upon clarification with this interviewee, he did not mind that another patient in the cubicle was present during his interview. The participant and this room-mate had in the previous day shared their stories about their hospitalisation. As a researcher, at the time it seemed there would be a minimum of impact upon the interview process because of these considerations. Upon reflection, even though the patient did not mind the presence of another patient hearing about his experiences, as a researcher I felt the interview process deviated from all previous interviews conducted in privacy. Because of this deviation, the interview of this particular participant was excluded from the data set.

The second interview with participants was an arranged appointment for which privacy was guaranteed. Interview rooms were booked and used if participants were coming in to the hospital, while some participants (six in total) were interviewed at their homes.

## **5.5 Collection of data**

The data sources collected for this research were the interview (Section 5.5.1) and the reflective account (Section 5.5.2), and are described in detail below.

### **5.5.1 Interview process**

The participants recruited were interviewed on two occasions. The first interview was in hospital before discharged home (or within two weeks of discharge) and was designated interview 1. Interview 1 was short, usually no longer than 30 minutes. The second interview was performed nine months after discharge and was designated interview 2. Interview 2 was open-ended, and usually about two hours long. Thirty three participants were initially interviewed for interview 1 and 29 participants for interview 2 (two people died before interview 2, and two people chose not to attend interview 2).

Before interview 1 or interview 2 could proceed, various initial physiological measurements were collected: blood biochemistry, vital signs, weight and height (Section 1.5) and the SF36 Health Status questionnaire. The procedures involved with the interview process and management of the interview data and how the SF36 data were utilised in the interview is discussed in Section 5.5.1.1 for interview 1 and Section 5.5.1.2 for interview 2.

### **5.5.1.1 Interview 1**

Interview 1 was carried out at the Heart and Lung unit of the regional hospital in which the participant was recruited before discharge, or similarly within two weeks of discharge home. A short more semi-structured interview took place in interview 1, recognising that participants may be tired and would not manage longer than half an hour. A total of 33 participants were interviewed at this stage. All interview 1 data was included except for one participant whose interview data was removed due to lack of privacy (see previous Section 5.4.3 for detail).

An interview schedule (Appendix 7) was used as a guide to ensure topics were covered consistently but not steadfastly, in order to avoid “context-stripping” (Miles & Huberman, 1994, p. 35). The first question of the SF36 questionnaire (“In general, would you say your health is: excellent, very good, good, fair or poor?”) was used as a starting point for the interview.

Participants were asked why they had answered the first question in the SF36 survey the way they had. Reiteration and asking for clarification was a useful way to commence each interview as participants had various justifications that served to lead on to some aspect of describing or interpreting illness. It also provided a consistent starting point for the interview for all participants; focusing both the participant and researcher.

Participants were also asked to answer some selected questions (Appendix 8), which were used only as prompts to stimulate discussion. Not all participants were asked all these questions, their inclusion was time dependent. As time permitted, participants were asked about their physiological measurements: electrocardiogram, blood pressure, pulse, blood results and discussion about various interventions with various documents (drug charts and vital signs charts) providing prompts which ultimately lead to a discussion of their experience and interpretation of illness at that time.

### **5.5.1.2 Interview 2**

Before proceeding with interview 2, the voice file for each participant for interview 1 was listened to again. This was an opportunity to reflect specifically on the participant’s state of health and illness and consider what particular additional questions could be asked other than those on the interview schedule. Additionally it was important to ensure blood results were available to take to the interview as the results were again triggers for questioning the participant about: access to the results, what the results indicate, what actions were taken as a result of blood tests, attendance of appointments with the family doctor and/or practice nurse or

other primary care providers, and what the plan was for continuing recovery and ensuring ongoing health.

Participants were interviewed in the outpatient departments of two hospitals or interviewed at their home if they were not well enough to meet at the hospital. The interview itself was approximately one hour, but meeting up with participants, checking personal details, taking physical measurements and sending the participants for blood tests (for the RICE study) usually extended the meeting time by an hour. Participants were sent for blood tests if they had not had an oral glucose tolerance test or a recent blood HbA1c.

The second interview had an interview schedule (Appendix 9) as guidance. This was essential as there were numerous central issues to revisit in this meeting. The schedule served as a prompt to the researcher to ask about specific facets of recovery and general well-being. The interview allowed opportunities to gain more in depth insights. The interview process was open, allowing opportunities for participants to ask questions and these would be answered, but always with encouragement to discuss the topic further with health professionals in charge of their care. Epistemically answering questions is in keeping with the participant's construction of knowledge, significant to the theoretical perspective of this research; ethically it encourages interaction with the participant-as-patient with their health professional.

In terms of sequence the interview commenced in the same manner as interview 1; asking participants to explain why they had answered question one of the SF36 questionnaire as they had, again using this question as a springboard for the interview. As for interview 1, participants were asked to answer some selected questions (Appendix 8). These questions were used only as prompts to stimulate discussion. Not all participants were asked all these questions as time did not always permit this. It was more important that the interview allowed for deviation from the set sequence of questioning, more exploratory discussion, and more time to recapitulate. Again this was tantamount to stimulate conversations that were largely driven by the participant with some (re)direction by the interviewer.

### **5.5.1.3 Management of interview data**

Interviews were all recorded, saved as a digital file to a password protected laptop, and kept by the researcher. None of the participants wanted a copy of their voice file even though this was offered. All files were saved to a CD and taken to a transcriber. The company handling the transcriptions asked all potential transcribers to sign the HDEC approved confidentiality agreement (Appendix 10). Once transcriptions were completed, the CD with voice files was

deleted or destroyed. Voice files and transcription files were saved on the researcher's laptop hard drive and the university's regular backup system (H drive), all password protected.

Participants had both transcribed interviews 1 and 2 sent to them for verification. Up to this point participants could withdraw from the study. A covering letter (Appendix 11) sent with both transcripts stipulated that if they wished to make changes to the transcripts could they please send back just the transcript pages that needed alteration in the return addressed envelope (or they could opt to send alterations by email). The covering letter also stipulated that participants had two weeks to send back their alterations from the date of the covering letter. If the researcher did not hear from the participant within two weeks of mailing out transcripts, the researcher assumed that no alteration was required and the original transcript could be analysed.

Two participants died before they could be interviewed a second time. Their interview 1 transcripts were still included in the interview 1 data pool as they had given consent to participate.

#### **5.5.1.4 Management of interview data using software**

Once interviews were verified the transcripts were uploaded to software NVivo 9 (QSR International, 2012). The software was used to initially facilitate and organise data during an initial analysis in to 'nodes'. This process is further detailed in Section 5.6.

#### **5.5.2 Reflective account**

Reflection offers an opportunity to situate self in the role as clinical researcher (Thorne, 2008). Reflection is particularly important for this research as methodologically and also epistemologically as it is essential to reroute knowledge back to the place it was harvested from, the practice setting.

A reflective journal was kept throughout the entire journey of the doctoral study. An account such as this keeps the researcher fixed in iterative interpretation, adding value to the research analysis. This form of self-reflection or reflexivity calls for careful reflection and interpretation (Alvesson & Sköldbberg, 2009). It is used in a methodological sense (Schwandt, 2007; Thorne, 2008), encourages frequent critical self-reflection on (electronic) paper.

The reflective journal maintained throughout the research, provided a mode for reflecting on what was actually executed before and during the interview. The journal provided a forum to

tabulate thoughts and comments on appearance of the participant, the environment the interview was held in, the emotional state of the participant during the interview, and their cognitive status. This reflective journal also provided an audit trail of events, documenting what occurred and also why events may have transpired. Thorne explains how this trail is often mentioned in research reporting but the significance of reflexivity is generally not overt, yet informs the inductive analytic process (Thorne, 2008; Thorne, Reimer Kirkham, et al., 2004).

An AEEC (appearance, environment, emotion, cognition of participant) tabulation from reflections noted in the reflective account for this research. The AEEC notes were a written recording made during reflection immediately after each interview. Each time a participant was interviewed the appearance of the participant was noted, as was the environment in which the interview was held, for example a private room as opposed to open four bedded cubicle. The emotional and cognitive state of the participant was surmised. This summary was important to record as patients in the unit still for interview 1 were often tired. All of the notes made were a reflective assessment of the participant at that point in time, hence this information is subjective and arguably gleaned from a clinician's perspective. An example of AEEC tabulation for interview 1 is shown in Table 5.1 for participant 2, and interview 2 is shown in Table 5.2 for participant 13 who was diagnosed with diabetes during the study.

## **5.6 Analysis of interview data**

Thorne writes about making sense of the data: “[it] is unquestionably the most painfully difficult and yet most essential element in what constitutes a credible interpretive description study” (Thorne, 2008, p. 141). On the strength of this point, analysis for this research concerns itself with conceptualisation of data at a level that demonstrates deeper synthesis (Sandelowski & Barroso, 2003; Thorne, 2008), to make sense of multilayered experience (Rayman & Ellison, 2004), remaining aware of assumptions made about the data (Miles & Huberman, 1994) as is realistic.

Analysis of qualitative data from the interviews is organised chronologically in the NVivo database. Interviews for visit one and visit two were analysed separately initially, then later when themes were formed the chronologically separate data were merged. Analysis takes seemingly disjointed dialogue, codifies the dialogue and then reconstructs the dialogue as an interpretation. In terms of interpretivism-constructivism, construction and reconstruction is indispensable. In terms of the data reconstruction or reassembling of data there is a possibility of misconstruction, detracting from the experience. Codes were therefore gradually identified, their relevance and coherence matched to reflect data, then discarded or saved accordingly.

**Table 5.1 Appearance, Environment, Emotion, Cognition (AEEC) tabulation: interview 1, participant 2, no prediabetes.**

<b>Participant 2</b> CPC02	<b>Interview 1</b>	<b>12/10/09</b> <b>Interview in heart and lung unit</b> <b>before discharge</b>
<b>Appearance</b>	Tall man, older, overweight, sounds breathless In pyjama pants and IV top Lying on the bed Tired, drained appearance, pale	
<b>Environment</b>	Interview in cubicle 14, quiet and away from ‘rush of unit’, single bed Lying in bed He mentions the TV doesn’t work, and I offered that this may be on purpose I suspect he feels a bit isolated	
<b>Emotion</b>	Has a sense of humour. Talks about stress being the cause of previous MI* Stress is less the cause of this MI, he explains that it is probably due to his smoking. He seems concerned about his predicament He is positive about his recovery but anxious about going home alone	
<b>Cognition</b>	Has a clear understanding of what has been going on to arrive here in CCU. He knows he has to make lifestyle changes: not smoke, eat less, be more active etc. He is alone, little support network around him.	
<b>Interpretive note</b>	Details of evolving illness are conspicuous: alcohol consumption has been high, over-eating plus eating high calorie and fat diet, little exercise. He explains he is not currently engaging in activities that indicate self-care. How interested is he in self-care of conspicuous detail?	

\*MI = myocardial infarction

**Table 5.2 Appearance, Environment, Emotion, Cognition (AEEC) tabulation and interpretation: interview 2, participant 13, diabetes diagnosed by General Practitioner**

Participant 13 CDW13	Interview 2	1/2/11 Interview in hospital outpatient department
<b>Appearance</b>	<p>Seems less care taken over appearance this time</p> <p>Deliberating over answers</p> <p>Lacks confidence</p> <p>Central weight</p> <p>Warm hands</p>	
<b>Environment</b>	<p>Room is windowless and claustrophobic</p> <p>Table with 2 chairs at the most, inhospitable, not ideal for an in depth interview</p> <p>Have to 'steal' equipment from neighbouring rooms</p>	
<b>Emotion</b>	<p>Chirpy and yet is down about his wife having dementia</p> <p>Wife has dementia since she had anaesthetic for a cholecystectomy</p> <p>During his conversations he tends to come back to his concerns about his wife, she was his support person and now she is not present (although alive), I hear him being drained by the constant of visiting his wife in a hospital</p> <p>There is a sense of being alone in coping with life</p>	
<b>Cognition</b>	<p>Has clear understanding of his condition of his heart</p> <p>When asked who his support person is he answers “I don’t seem to have one”.</p> <p>Resents that several health professionals have told him there is little they can do for him (has diffuse disease of coronary arteries)</p> <p>Cardiologist has said there is little they can do</p> <p>He recalls again the comment made by a nurse, that he should go home and smell the roses</p> <p>Mr X has not had a conversation with his GP to explain he has dysglycaemia, and is likely to have prediabetes, when his recent blood tests indicate he has a sustained high blood glucose hence diabetes.</p>	
<b>Interpretive note</b>	<p>He has given much to the wider community and needs a little attention back now caring for self</p> <p>Has loving family that care about him but are not always able to be there for Mr X, feeling isolated, lonely with wife in care</p> <p>Isolation because of social situation (family, wife) and illness</p> <p>Who does he have a caring dialogue with?</p>	

### **5.6.1 Preparation for analysis**

After the interviews were completed a reflective note was generated. First a reflective note was made in the reflective account (Section 5.5.2), immediately after all interviews about: emotion, cognition, the interview environment and the appearance of the participant, known as the AEEC table as discussed in Section 5.5.2. These reflective notes were married up with the interview transcript to aid interpretation and ultimately understanding, as a point of thoroughness. The AEEC notes were brief and are therefore tabulated (Tables 5.1 and 5.2).

The aim of the AEEC tabulation was to dovetail descriptions from the reflective account with the thematic framework developed (Section 5.5). This information is then assembled together as an interpretive note to construct meaning back to the overarching theme, in/conspicuous detail. The theory behind this amassing of data is to gain the best insights into participants' experiences. The interview's intention is to gain access to the subjective experience, while the additional observational notes made are a description of contextual elements. For example the interviews often did not reflect how exhausted participants were in hospital. This element of exhaustion was often noted after the interview when completing an AEEC reflection. Integrating interview data with observations made by the interviewer added another layer of description and interpretation. The gravity and intensity of recuperation from a myocardial infarction was emphasised by using the additional AEEC reflection, enhancing quality of data construction (Thorne, 2008). Today more researchers are using a multi-method approach to attain a more in depth perspective for better results (Fontana & Frey, 2005). This research is not a multi-method study, nevertheless gathering data from multiple sources (reflective account, interviews) improved my understanding of what was observed and heard throughout the interview, potentially enhancing data quality.

During the period of interviewing, there was a further level of reflection concentrating on process; hence the recording of process in an electronic file entitled "what I actually did". The interviews were professionally transcribed; however, time was spent listening to the interviews with the transcripts, making oneself familiar with the interview data, also making notes in "what I actually did". During this time of familiarisation, concept(s) were already formulating as themes, toward forming research findings.

### **5.6.2 Preliminary thematic analysis**

Analysis was an inductive process based on Thorne's (2008) theoretical advice recommending that the process be data-driven, as opposed to theory-driven or driven by a predetermined process. Analysis is a journey of thinking (Smythe, et al., 2008) which is not about the same

literal topic recurring (although this may be the case), but more an “understanding we have seen something that matters significantly . . . [hence] the understanding that is evoked by thinking and re-thinking the experiences participants share always keeping new understandings in play and offering them to readers to further explore” (Smythe, et al., 2008, pp. 1392-1393).

Paper copies of the interviews were read and reread to identify themes. Themes were compared across a random sample (6 interviews) of all 33 interviews. Using the sample of six interviews, a theme code was created, its reliability determined by looking for similar themes across interviews outside the sample of six. Finally the theme was added to a list of themes to be applied to the entire interview set (for both interviews 1 and 2).

Not all the participants were recruited and interviewed in hospital for interview 1, because they were discharged swiftly. Therefore the sample of six interview transcripts reflected the various times that people were interviewed: three interviews of hospitalised participants and three interviews of participants recruited after they were discharged home. For interview 2 some participants were interviewed in their homes and others in an outpatient department of a local hospital. A second sample of interviews were coded for themes, reflecting those interviewed at home or those interviewed at the outpatient department.

The theoretical perspective of this study maintains there are multiple realities and therefore that knowledge is multiperspectival (Schwandt, 2007). Analytically, this demands that what seems anomalous to the researcher is not likely to be to the participant. Therefore the participants’ interpretation is in turn always adding to the prospective depth and authenticity of the researcher’s interpretation.

### **5.6.3 Ongoing iterative analysis**

Ongoing analysis required a great deal of structuring and restructuring of data using the coding, to be satisfied as a researcher that the presentation of data was credible (Thorne, 2008).

Throughout the process of coding, interview excerpts considered important were grouped, regrouped, formed patterns, relationships between excerpts scrutinised, relationships confirmed or rejected, progressed to more specific themes, followed by coding multiple times. Using this approach interview excerpts transformed into themes which in turn evolved into a framework.

There followed a period of returning to the interview transcripts and voice files, to examine aspects of the data that were potentially missed or of concern in terms of theme development. This was followed by rereading the interview transcripts to acquire a sense of ‘the whole’, to be satisfied that the analysis had produced an interpretation that is credible.

Further layers to ongoing analysis included: process of analysing using NVivo 9 software (Section 5.6.3.1), developing nodes to themes as a paper exercise (Section 5.6.3.2), and engaging colleagues to critique thematic findings (Section 5.6.3.2).

### **5.6.3.1 Analysis using NVivo 9 software**

Using NVivo 9, similar interview excerpts were coded as a node, so an entire interview could be chunked into excerpts and sorted into as many as 85 nodes. Some interview excerpts were saved into multiple nodes. As coding continued, any interview excerpts coded at established nodes were constantly reviewed to ascertain consistency. In the beginning this meant interview excerpts needed to be reassigned to different nodes. For example the node “medications” later had sub-nodes created as interview excerpts concentrated on specific drugs. Recoding to “aspirin”, “ACE inhibitors”, “antihypertensive medication”, “anticoagulants” and so on. Meticulous reiteration of coding ensured a thorough understanding of the themes. Used in this manner NVivo allowed for the management and some level of analysis of a large bank of data, without the loss of inductive thinking (Thorne, 2008).

Memos were developed in the NVivo9 software at commencement of analysis. The memos were ideas, thoughts, and later links to the theoretical perspective that needed to be immediately pulled in to the analysis. A number of the memos were copied into the reflective account and expanded to become part of the supporting explanation of the thematic framework presented in Chapter 6. Having the memo tab available in the NVivo software provided a constant stimulus to link in the theoretical lens as much as possible.

### **5.6.3.2 Coding**

The naming of nodes was initially not very inventive, more descriptive. Coding of the interviews took at least two weeks, during which time the more descriptive codes gradually shifted to more interpretive language. As an example a group of interview excerpts were grouped together as “miscellaneous” which eventually was re-coded as “detours & distractions” because these were excerpts about the lives of the participants. Participants had chosen to discuss personal information which was not directly related to the main topic, but it still contextualised who they are. This highlights a further coding dilemma, spending too much energy on getting it working well from the outset, and making codes too specific. Thorne (2008) discusses this point in depth recommending that coding is best kept broad and generic until analysis is further developed. In agreement with Thorne, Miles and Huberman (1994) explain

that coding requires recognising what data matters in order to answer the research question, and what data does not necessitate consideration. This research worked on the proviso that virtually everything mattered, predominantly to keep data contextualised.

### **5.6.3.3 Theme development**

The process of shifting from NVivo nodes to a paper drawn scheme of themes occurred over an afternoon. The nodes on the software had acted as an initial holding-pen for the interview excerpts. Their descriptive labels were reconsidered and some given a more interpretive meaning. Nodes with similar themes were collapsed into one theme. Over the course of a few weeks a framework was drafted which grew to become the thematic framework presented in Chapter 6. Many drafts (eight to be exact) of the thematic framework were shared with supervisors, colleagues and people with illness not involved in this research. After each supervision meeting there were always new points to consider which required returning to the interviews, staying open to the data, refocusing on the larger framework, and becoming engrossed in understanding what this all could mean.

The subthemes for the two major themes revealed a number of clustered notions which were found to be common across most interviews. These notions were called embedded subthemes and were discovered while simultaneously analysing data and writing findings Chapters 7 and 8. The embedded subthemes assisted in recognising further aspects of illness, therefore the embedded subtheme was important to help distil the meaning of the related subtheme. Further explanation and examples of embedded subthemes are found in Chapter 7, Section 7.1 and Chapter 8, Section 8.1 respectively.

## **5.7 Emergent interpretation**

The aim of this study was to gain insight into experience and understanding such that “the constructions that people (including the inquirer) initially hold, aiming toward consensus but still open to new interpretations as information and sophistication improve” (Guba & Lincoln, 1994, p. 113). Some qualitative researchers claim that returning to the participant with an interpretation is essential (Dahlberg, et al., 2001); while other researchers claim that any interpretation is an interpretation of the researcher alone (Melia, 2010), such that the researcher is entrusted with a representation of the experience with sensitivity to historical and contextual insight.

Ontologically this research subscribes to multiple realities (Alcoff, 2011); for this reason validation is not considered an absolute priority. As the researcher, I did not specifically send a

summary of the research to participants for validation, hence avoiding some of the debate of potentially shifting analytic authority to the participant (Morse, 1999). I did have some email contact with participants about the content of interviews but this was viewed as an opportunity to remain engaged with the research, rather than an intellectual exercise to reconstruct knowledge with the participant.

Thematic insights were drawn from working in the clinical setting (neurosurgical ward, not directly related to ACS or prediabetes) in November and December 2012. Thorne describes this as “analytic inspiration” (2008, p. 152), although this phrase may be somewhat out of context as she refers to interpretive technique. Working in the clinical setting afforded reflection upon the more abstract framework being developed and how it might apply to patients in the neurosurgical setting with complex illness. It was noted that patients were embattled and in an experience that was clearly their own reality and open to their own interpretations.

### **5.7.1 Verification of interpretation with supervisors**

Three two hour meetings were held with supervisors to determine: coding of interviews, language used to describe NVivo nodes and the interpretive nature of nodes (later to become themes). All three supervisors participated in these meetings. Further verification meetings were held fortnightly while analysis was developed over a three month period. Meetings concentrated on becoming more interpretive, letting the meaning come, staying open to the data. It became clearer that interpretation was not only about interpreting the actual data, it also incorporated how the data was structured and presented in terms of the thematic framework. For this reason the verification process was essential to address data integrity, maintaining an overt process sustaining the development of authentic interpretation.

## **5.8 Conclusion**

This chapter has summarised how the research study was undertaken with details of the two principal methods used: interviewing and maintaining a reflective account. The interview was the chief source of data collected, although the reflective account was equally important for ensuring a level of data integrity. Data collection and development always related to the theoretical perspective of the research. For this research, ontologically reality is indirectly constructed, subjective and multiperspectival. Undertaking interviews was an ideal method to begin to draw out the multiple individual meanings that participants established from their experiences of illness. The actual process of the research is thus described. In Chapters 6, 7 and 8 the study findings are presented.

## Chapter 6

### Descriptive findings: thematic framework

#### 6.1 Introduction

This chapter presents the findings of the thematic analysis in a descriptive thematic framework. The chapter starts with an overview of the thematic framework in a tabular format (Table 6.1). This tabular overview helps describe how the framework was constructed, and how it answered the two research questions:

1. What is the experience of people who are admitted to hospital with an acute coronary syndrome event and then find they also have high blood glucose, and what is their interpretation of their complex illness?
2. What is the experience of people who are discharged from hospital back to the community after an acute coronary syndrome event and also have high blood glucose, and what is their interpretation of their complex illness?

Then follows closer examination of the framework, showing a link to the theoretical perspective, as described in Chapter 3. Further into the chapter each theme of the framework is described and illustrative excerpts from interview transcripts help demonstrate how themes evolved.

Overall this chapter represents a narrative of what the participants expressed over two interviews (62 interviews in total). The participants recounted many experiences and disclosed extensive insight into living with illness; the material collected from the interviews was rich in information specific to living with complex illness.

#### 6.2 Thematic framework

The analysis of the interviews led to the construction of a framework that represents the interview data (interviews 1 and 2). Themes were first developed from NVivo 'nodes'. Further iterative thematic analysis (see Section 5.6.3) created themes, which were then redeveloped to finally assemble the thematic framework. The description of subthemes was important to develop before the interpretation of the interviews is offered. The subtheme description was kept at hand as transcripts were scrutinised and portions of interviews were saved as potential excerpts to include in findings chapters. The subtheme description was important to ensure consistency of multiple interview excerpts, which may have represented a subtheme. The

description also ensured some consistent delineation between themes. For example, the difference between subthemes restorative dialogue and caring was what the participant discussed about their condition and how motivated they were to change life style habits that could improve their health (dialogue) versus what the participant explained they actually had done (caring). It was important to gather numerous interview excerpts for any one theme or subtheme from different participant interviews to reinforce the distinction between themes.

The framework was constructed as an analytical representation of the similarities participants expressed in their separate interviews. Naturally the stories that they conveyed also revealed difference. A dialogic process of working with the data, with the transcriptions proceeded: reading and rereading, listening to the voice files again and thinking it through (Smythe, et al., 2008). Participants revealed similar experiences that are assembled as a thematic framework as in Table 6.1.

**Table 6.1: Thematic framework: Representing participants’ experience and interpretation of complex illness**

<b>Over-arching theme</b>	<b>In/conspicuous detail</b>					
<b>Major theme</b>	<b>Invisible disequilibrium</b>			<b>Dialogue as caring</b>		
<b>Sub-themes</b>	<b>Losing equilibrium</b>	<b>Becoming Embattled</b>	<b>Evolving illness</b>	<b>Restorative dialogue</b>	<b>Caring</b>	<b>(Re)-constructing illness</b>
Description of subthemes	Equilibrium is breached so participant becomes aware “something is wrong”.	Facing an invisible unknown.  Chaotic expression, emotional and psychosocial disarray.	Disequilibrium is becoming visible.  Commenting on immediate past events, reflective.	Dialogue with patient and family or significant others.  Talking with participant, patient.  Becoming motivated.	Self-care.  Participant stating what they have done to improve health.  Having a plan.	Acknowledging ill health.  Demonstrating some understanding of self within illness.

The themes are not a rigid progression of how participants laboured through a particular process in order to construct an understanding of illness. The themes are there to stimulate understanding, encouraging reflection upon the experiences participants shared with the researcher.

The framework aims to convey how the organised themes characterise particular meaning, equally the wording of the themes aims to promote thinking by using the very words that best represent the theme. For example the overarching theme is in/conspicuous detail. This theme evokes thinking about details or particulars that are hidden and/or obvious. From a constructivist stand point, it is of interest to understand how detail can be hidden or overt in constructions of knowledge. The subtheme becoming embattled developed because some participants dwelled on their reaction to their ACS event, participants expressed some emotional and psychosocial disarray. The title of the theme that holds this information should indicate this, hence the wording becoming embattled, an evolving phenomenon.

The major theme invisible disequilibrium continues a language of the hidden and/or the obvious (in/conspicuous detail). The disequilibrium refers to the body's homeostatic ability to maintain equilibrium which has become unbalanced. This theme has three subthemes: losing equilibrium, becoming embattled and evolving illness. The experience of invisible disequilibrium, through loss of equilibrium and/or embattlement, brought with it an evolving understanding of illness. Participants talked about losing equilibrium which was not obvious to them. Some participants spoke more about the phenomena of one subtheme than another, so participant experiences showed wide-ranging commonality, but the experiences themselves are what makes them unique.

Participants also informed me as the listener, that therapeutic caring occurred through dialogue with significant others, friends and health professionals. Thus the second major theme was entitled dialogue as caring. This major theme embraces the understanding of how participants constructed knowledge about illness through dialogue. Three subthemes are embedded as: restorative dialogue, caring, and (re)constructing illness. These subthemes indicate turning points: becoming motivated (restorative dialogue), having a plan (caring), and understanding self in illness (constructing illness). During the interviews, participants explained how they made sense of the dialogue with others concerning their illness, how they were motivated to improve their health, planned how to recover, and developed their own construction or reconstruction of illness through understanding. Understanding in turn was dependent on their insight of in/conspicuous detail.

On the following pages table 6.2 provides a more detailed tabulation of the framework. This table again features each major theme and subtheme. Additional supporting information is the row underpinning theoretical concept or notion in table 6.2. This aims to link the theme to the theoretical perspective of the research. The concepts are mainly derived from Gadamer's work, but other authors are also included. Jonsdottir Litchfield and Pharris (2004) have written about dialogue as central to nursing care. They explain how dialogue is the remaining open to the

**Table 6.2 Comprehensive Thematic Framework (extended framework from Table 6.1)**

<b>Over-arching theme</b>	<b>In/conspicuous detail</b>					
<b>Major theme</b>	<b>Invisible disequilibrium</b>			<b>Dialogue as caring</b>		
Underpinning theoretical concept or notion	<p>“... sickness and loss of equilibrium, do not merely represent a medical-biological state of affairs, but also a life-historical and social process.” (Gadamer, 1993/1996, p. 42)</p>			<p>In a dialogue of caring, the participant expresses what they understand from their experience. A dialogue (with significant others or health professionals) clarifies or improves the visibility of various facets of illness for the participant (as patient), at counterpoint to interpreting and understanding an evolving construction of illness. “... it is only through a disturbance of the whole that a genuine consciousness of the problem and a genuine concentration of thought upon it can rise” (Gadamer, 1993/1996, p. 73).                      “... the nurse is present to the patient in an open caring attentiveness to whatever emerges in their dialogue” (Jonsdottir, et al., 2004, p. 242).</p>		
<b>Sub-themes</b>	<b>Loosing equilibrium</b>	<b>Becoming Embattled</b>	<b>Evolving illness</b>	<b>Restorative dialogue</b>	<b>Caring</b>	<b>(Re)constructing illness</b>
Underpinning theoretical concept or notion	<p>Equilibrium is multi-faceted (physical, mental, social etc)                      “...illness represents a fall from self-sustaining equilibrium into a state of unbalance” (Gadamer, 1993/1996, p. 55)                      Disequilibrium is no longer likely but imminent                      Disequilibrium is invisible.</p>	<p>Participant seems embattled as equilibrium diminishes                       Punctum caecum, blindness of the consciousness (Merleau-Ponty, 1964/1968) p.248.                       “... illness can make us insistently aware of our bodily nature by creating a disturbance in something which normally, in its very freedom from disturbance, almost</p>	<p>Disequilibrium becomes visible                      Equilibrium is lost sufficiently so disequilibrium becomes visible.                      “Illness, then, is in general experienced by the person who is ill as a disturbance which can no longer be ignored”(Gadamer, 1993/1996, p. 55)                      An increment of chaos, discernible disconnect, inevitability</p>	<p>“The recognition that something is lacking is connected with the idea of balance, and this means in particular with the idea of a restoration of equilibrium” (Gadamer, 1993/1996, p. 55).                      Attempts are made to restore equilibrium through dialogue between patients, their families and/or significant others and health professionals.                       Dialogue is how the participant-interviewer rapport proceeds; the nurse is open (fully</p>	<p>As: caring for self; or caring for patient by others (family, health professionals).                       Caring for patients such as these participants is about making inconspicuous details overt or visible to the patient through iterative restorative dialogue. Through nursing care the patient and nurse endeavour to reconstruct balance, a time of ‘doing’, as confidence grows; state of illness begins (re)construction.                       “It is part of the balancing act of life that one learns to forget what is causing a disturbance,</p>	<p>Meaning of illness as constructed by the person with illness.                       Making sense of particular detail (of illness) which the patient/participant then does/does not act upon, to re-establish equilibrium                       Still may have disequilibrium but concerted attempts are made to (un)successfully restore equilibrium. Equilibrium as previously known to the participant may only be restored partially. Health is reconstructed through restorative dialogue</p>

		completely escapes our attention” (Gadamer, 1993/1996, p. 73)  Loosing equilibrium and becoming embattled intertwine; the former is less tangible by the participant but will be noted by an expert health professional.		present to patients) to the dialogue about what ever health predicament the participant/patient talks about (Jonsdottir, et al., 2004, p. 247) so the nurse is open to a dialogue with patients to deal with their health predicament, what does the patient think their needs are. Increasing visibility of illness. A time of questions, discussion	or at least succeeds in regarding it with indifference. One of the means for sustaining this skill of balancing is precisely intelligent behaviour (Gadamer, 1993/1996, p. 55) Intelligent behaviour = all that re-establish/restore equilibrium. Gadamer’s intelligent behaviour is a metaphor for the nurse-patient relationship “emerges as a caring process with meaning unfolding through the dialogue” (Jonsdottir, et al., 2004, p. 243). The relationship is professional and empathetic.	and caring. This includes new constructions of life routines.  “The challenge is the continual one of sustaining our own internal balance within a larger social whole which requires both cooperation and participation” (Gadamer, 1993/1996, p. 81)
Original NVivo Nodes (themes)	No/warning Admission to CCU- Events prior to hospital admission Alcohol use Being breathless Diet Embodiment Exercise Family medical history Hypertension Medical history Medications Pain Sleep Smoking	No/confidence Mis-diagnosis Events prior to hospital admission Being a patient Distractions Embattlement Health care v health care Medications Pain Stress	No/confidence Mis-diagnosis Interpreting-hospitalisation READMISSION* SF36 QUESTION* SUPPORT PERSON* Family New diagnosis: prediabetes Pain Being inquisitive Risk as . . .	Being a participant Being inquisitive Cardiac rehabilitation programme Current health Discuss pathophysiology HAVING DIABETES* Health information, IT Interruption Medications Patterns of behave PH providers RELIVING * RISK* Surgery, interventions Health care v health Questions LIVING WITH PAIN*	Commitments HAVING DIABETES* Prevention of illness Questions: what is MI? RELIVING* SELF-CARE* RISK* Weight work	Interpretation of hospitalisation Commitments Current health Prevention of illness Health care v health Interruption Medications: interpret NEW JOB(WORK)* LIVING WITH PAIN* Participant interpretation of illness Reflecting on the past to interpret for tomorrow HAVING DIABETES*
Acquisition of themes	Themes and concepts mainly from interview 1			Themes and concepts mainly from interview 2		

\* = node developed when data managing interview 2 (also in capital letters), those without \* are nodes developed during data management of interview 1.

needs of the patient (participant), the needs of a person living with illness. For this research the interviewer made all efforts to remain open to what the participant shared in the interview. The dialogue refers to the experiences and interpretation of illness and how this contributed to a construction of illness.

The original NVivo 'nodes' (themes) are also included in Table 6.2 to add further clarity, showing how subthemes and major themes were formed. One node may be found across several subthemes such as the node HAVING DIABETES. This particular node had interview excerpts that informed the subthemes restorative dialogue, caring and the (re)construction of illness.

In the following sections each theme (overarching, major and subthemes) is represented by several interview excerpts that demonstrate the essence of each theme.

### **6.3 In/conspicuous detail**

The overarching theme inconspicuous and/or conspicuous detail is about the detail or elements of living with illness or health, be that detail visible to the participant or invisible. When this theme was developed it became clear that detail was paradoxical, that detail could be both conspicuous and inconspicuous. This is particularly in keeping with an interpretive perspective where the binary state is sidestepped; there is fluidity between one and the other. For this reason, the word detail is used in preference to details, indicating all is one state, constantly evolving between being conspicuous and being inconspicuous dependent on the narrator of the detail. Stating detail in one of its binary states (as inconspicuous detail or conspicuous detail) seems slightly contradictory but acts as a starting point in description or interpretation of the detail. For example a participant may have found that detail seemed inconspicuous to them but perhaps not to a clinician. A clinical example is as follows: a patient comes to hospital with vague chest pain and blood tests find their cardiac enzymes are significantly raised to indicate a myocardial infarction but the nurse also notices their HbA1c is also raised. The chest pain will have been conspicuous to the participant (as narrator), while the confirmable diagnoses are additional conspicuous detail to the nurse (as narrator) but are inconspicuous detail to the participant.

An interview excerpt follows indicating in/conspicuous detail:

I went in . . . to the nurse, just to get my blood pressure checked. It was so high, then I confessed that I'd had chest pains for some months which I'd just ignored, just got on with what I was doing. And they took one look at my blood pressure level which was 204 over something . . . and they shot me in an ambulance in here [the hospital].  
(CDM10, int1, p.2-3)

The quote has both inconspicuous (invisible) and conspicuous (visible) detail expressed by the participant as narrator. This participant has a suspicion that all was not well, she experienced this even if it was not overt, but it was real to her i.e. not yet able to be interpreted, therefore inconspicuous. The feeling was confirmed as details became conspicuous by taking a blood pressure recording and finding it was high. In the act of interpreting the blood pressure as high, detail became conspicuous. The participant explained she had chest pain for some months also indicates conspicuous detail. Added to this, the participant had conspicuous detail (chest pain) for some time but chose when to make it conspicuous to others. Therefore, the equilibrium of the body and mind are 'at sea', that a lesser disequilibrium moves toward an overt chaotic disequilibrium.

The same participant tells the researcher that they were hospitalised to have further investigations:

. . . the following week I presented here [in hospital] in an ambulance with the beginnings of a heart attack. . . . this time Dr [ ] said, 'right straight to an angiogram', so the next day I had an angiogram, two blocked arteries, two stents and home the next day. . . feeling fantastic. (CDM10, int1, p.2-4)

There is a transitioning of inconspicuous to conspicuous detail, the tension of "the beginnings of a heart attack", and from there being able to make meaning from this detail as it becomes more conspicuous. The overarching theme is about being able to coherently express how the binary nature of the detail as stated by the participant, is more than a dichotomy. The researcher's reinterpretation concerns itself with explaining the space in between in a more conceptual form. From the two short excerpts offered above the interpreted abstraction is about self-deception. This example highlights a relatively common prevarication wherein an aspect of illness (e.g. this example being chest pain) is ignored through "self-deception or the knowing refusal to accept the truth of one's own illness" (Gadamer, 1993/1996, p. 55).

In/conspicuous detail refers to an evolving illness not yet identified, such as protracted high blood glucose. The in/conspicuous detail may remain largely unnoticed by the participant:

I have really only been focusing on the heart issue . . . I don't have much understanding of what level of risk I'm at with the diabetes thing, like at the moment saying I don't have diabetes but could develop it. (CRS34, int1, p.2)

The participant explained he had been focussed on the conspicuous detail of his heart, not so much the inconspicuous detail of high blood glucose. The participant related diabetes to his construction of illness as a conspicuous detail. He did relate to an inconspicuous state, "could develop it", but explained that "I don't have much understanding of what level of risk", so was seeking to make detail clearer (conspicuous) for himself.

These are examples of the inconspicuous and/or conspicuous detail (visible and invisible elements) of complex illness contributing to participants' constructions of illness. The major themes, invisible disequilibrium and dialogue as caring sit within the overarching theme in/conspicuous detail. These two major themes are considered next with their respective subthemes. Throughout the descriptions of the themes, inconspicuous and/or conspicuous detail will also be highlighted to illustrate how detail permeates major themes and subthemes.

## **6.4 Invisible disequilibrium**

The first major theme invisible disequilibrium is accounted for by three subthemes: losing equilibrium, becoming embattled and evolving illness. The main thrust of this major theme is that participants relate how they became ill, explaining the experience of illness, explaining what happened up to the point of the interview (interview 1). There is a tension of disequilibrium building which is represented by the subtheme losing equilibrium. The equilibrium referred to here is inclusive of biological balance, and life as historical and social process (Gadamer, 1993/1996). Equilibrium is therefore, a combination of psychosocial and biological aspects that together are constantly attaining and regaining balance. Participants described how their being destabilised, and what happened because of this loss of equilibrium. They described times of embattlement, feeling angered or frustrated about illness interrupting their life. This is represented in the subtheme becoming embattled. The last subtheme evolving illness found participants reflecting upon the events before and during hospitalisation. In summary, three subthemes represent recurring ideas from interviews that relate to the notion of an invisible disequilibrium.

### **6.4.1 Losing equilibrium**

Participants recounted about innumerable moments of their life both before and during their hospitalisation emphasising how their equilibrium was breached. The meaning of equilibrium here is positive (c.f. disequilibrium in the major theme title) referring more to a surfacing state that has hope of being turned around to equilibrium again. Equilibrium is a constantly self-correcting state. The word 'losing' emulates energy dissipating as equilibrium is gradually lost.

The following participant was interviewed in hospital soon after his admission to the cardiac care unit. He explains the events that gradually led to his admission to hospital:

I developed a very bad cough . . . was looked at by a doctor . . . not my own GP . . . it was an infection and it needed some antibiotics. Then, he told me, if it was not okay within a week, then go and see my regular doctor, but the antibiotics did lower it slightly – enough for me to not be so alarmed . . . but then it kept coming up and it became persistent [cough]. So, I went to see the [family] doctor . . . he said here's some antibiotics, but only take them if it doesn't get better, and it didn't get better . . . by then I kind of felt discouraged about going back, because I was banging my head against a brick wall.

The cough went on and on, eventually in addition to the cough I started getting chest pains, and it was only after walking exercise . . . and I'd take a Gaviscon<sup>2</sup> thinking that it must be a reflux problem. So, I went on in that vein for a few months, but the frequency of the attacks – pain attacks – got more frequent . . . so, I went back to the doctor and said I'm depressed about this, because I don't know what it is, and could we find out definitively – get diagnosed, so that I can do something about it? (CDP20, int1,p.1-2)

From this interview excerpt fear of the unknown (inconspicuous detail) and pain (conspicuous detail) made some of the invisible visible. The excerpt also generates a feeling of tension from this participant, his equilibrium in terms of coping with living with an unknown is creating imbalance. The participant was placing emphasis on diagnosis, to make detail conspicuous. He was relying on health professionals to reveal inconspicuous detail as there was evidence i.e. pain (conspicuous detail) which tells him that all was not well.

The following subtheme, becoming embattled, is closely related to losing equilibrium in that the embattled participant is portrayed as an emotional being. Becoming embattled therefore adds to the composite picture of the participant coping with complex illness.

#### **6.4.2 Becoming embattled**

The second subtheme of major theme invisible disequilibrium, is becoming embattled. Even though the combination of these two words is challenging to put into a sentence, I have kept this phrase preserved. The main reason for this is that it tells the reader that the participant was becoming or moving toward something but not quite there, in this case approaching embattlement. The word embattled has been used instead of the noun because it accentuates becoming which in turn places accent on a dynamic situation that is becoming embattled. Becoming looks to the future, embattled implies looking back; hence the oblique sense of being between worlds, the world that is familiar and that far less familiar as equilibrium is altered.

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<sup>2</sup> Used as an oral preparation for the relief of heartburn, acid indigestion, available over the counter in pharmacies

The word embattled used to indicate this theme takes its meaning as taking up of position in battle. This is not literal, really more a metaphor of how the body of the participant battles on to maintain equilibrium. Added to this is the psychosocial toll of constantly readying oneself for and fending off a state of imbalance or disequilibrium. Becoming embattled refers to how the participant attempted to successfully or unsuccessfully fend off the invisible disequilibrium, and notably how this affected them emotionally and psychosocially. Communication became strained, and relationships are tested, as the following excerpts show.

Continuing with participant 20, we step back and look at the point where becoming embattled was significant:

It [chest pain] got increasingly bad in Sydney. I had one very bad attack getting on a train there . . . and once these attacks subside then everything's fine you see. So, you tend to put it in the back of your mind again and say well maybe it will never happen again, but unfortunately it kept happening. . . we got back to New Zealand, and then I started to get attacks during the night for no reason, I was losing sleep because the pain was that intense. Then, Friday . . . I had about three attacks that evening – each one more severe than the other . . . It was so intense I was screaming and I lost control – emotions, everything. I was swearing at the doctor [on the phone]. I was so angry, and the local ambulance at the time wasn't available. So, they had to send one from [another town] . . . they were really fast those guys. They're just saints. So, they eventually arrived and calmed me down. They had to give me two shots of morphine. The pain was just unbelievable, and they took me to hospital. (CDP20, int1, p.2-3)

Even though this is a dramatic account, it does demonstrate how embattled this participant had become. He had already seen his doctor on several occasions for chest pain but there were no direct links found to a cardiac problem, the family doctor thought it was a gastrointestinal problem so prescribed Losec<sup>3</sup>. This same man (CDP20) was in the process of being referred to a physician in the hospital, the referral had taken longer than anticipated to process therefore an appointment was still pending. In the interim he went to visit family in Australia as he had had some assurance that his pain was probably a gastrointestinal complaint yet to be investigated. While in Sydney he experienced chest pain and then again when he got home he experienced significant chest pain as described in the above interview excerpt. This incident finally made detail conspicuous to others (the doctor on the phone and ambulance staff). The participant had reached a point where he knew he was losing equilibrium, he had always been aware of the conspicuous detail, it was always there. This interview excerpt also demonstrates how the participant was significantly embattled on the night of his chest pain that ended in hospitalisation, so much so that he lost his patience with medical staff “I was swearing at the doctor”. It is likely that he felt intense frustration at not being able to make what was conspicuous to him, conspicuous to others.

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<sup>3</sup> Omeprazole: proton pump inhibitor, used for treatment or prevention of reflux, duodenal and gastric ulceration.

Participant 17 had a different experience of becoming embattled. This participant had coronary artery bypass surgery. About eight months after surgery changes in function were noticed by her and her partner:

I didn't feel well in myself . . . I didn't seem to be doing anything . . . I didn't want to do anything. I wouldn't say that I was depressed or anything like that but I just didn't want to bother. . . [I] was like something that has been wound up was slowly just starting to . . . slowly wearing out and just going down and down and down . . . I [would get] angry quite quickly. So I mean I'm not sure what that actually was or whether it was something to do with the bleed in my head, I don't know. (CMR17, int2, p.2)

The participant sensed an invisible disequilibrium was developing, something was slowly changing. The bleed in her head was a cerebral aneurysm which was found to be slowly bleeding further, causing various neurological signs and symptoms that weren't quite tangible, details remaining mostly inconspicuous.

When asked if the participant's family noticed changes in their behaviour the reply was:

Well, I think [the partner] saw it. . . I'm [asking] had [they] seen anything sort of different in me, and [they] said, "Well, you know what you were like in November," which [they proceeded to] remind me of. And I found that things [the partner] did were annoying me, I was getting quite aggravated. (CMR17, int2, p.2)

The participant was becoming embattled, her behaviour was changing both because of the bleeding from her aneurysm (which remained an inconspicuous detail), and also from the tension and anxiety of not knowing what was happening to her. When asked if the participant had considered going to the doctor she replied:

I didn't bother going [to the family doctor] . . . I felt okay, sort of just felt not well but nothing I could have gone to the doctor and said I've got pains my chest or I'm feeling depressed or . . . You've got to have something to go with. Just I didn't feel right, something was going on and I couldn't figure out what it was. And I hate running to the doctor's anyway so I'd rather put it off unless I had to. . . although she [the family doctor] was outwardly OK . . . I think inwardly I was thinking to myself, she's [the family doctor] putting me in a little box because she [the family doctor] knows I've had all this trouble with [family members having depression] and [elderly in-laws] I had to go up to be with them because my father-in-law fell over and he had no-one to take care of [the wife with dementia]. (CMR17, int2, p.3)

The reaction the participant anticipated from the family doctor contributed to her becoming embattled. The relationship with the family doctor had deteriorated as the doctor knew there were family difficulties with so many issues that the participant had to manage. These issues included: dealing with a depressed family member, supporting a partner as they had a stressful job (not included in the excerpt above), caring for elderly family members in another town, plus transitioning them to a community care institution as well as selling their family home.

The participant related how there was further distress to unfold:

I was starting to feel really exhausted and [her partner] was sort of saying to me, “You’re not really well,” and I’m saying, “I’m okay, I’m okay,” . . . and I started to get the headache. And so it sort of went through to Christmas Day, so I had three weeks’ headache. Kept going back to the doctors and she kept saying, “Oh, it’s just the stress, you’ve had so much stress lately” and what have you . . . she knew what was going on with the folks because I had told her about that and so she said, “Oh, I think it’s probably psychological,” you know, and I immediately took that as being completely nuts - you think of psychological being just not quite all there and of course I took offence to that, so that didn’t help . . . then [their partner] noticed that I was doing some strange things - I’d say to him, “I can’t turn on the television because I don’t know how to do it,” so he said, “You’ve got to go back to the doctor.” So I went back to the doctors between Christmas and New Year and I said to her, “I think I’m losing my mind, I can’t remember how to do things,” and she said, “It’s just still the stress you’ve got” . . . [Doctor said] “I wonder if you’ve got something wrong with your neck,” cause my neck was sore. She [the doctor] said, “I think I’ll send you to the physiotherapist and have an x-ray” (CMR17, int2, p.4)

The sequence of events was such that participant 17 was beginning to lose patience with her family doctor “I took offence to that” and she was well on the way to becoming embattled “I immediately took that as being completely nuts - you think of psychological being just not quite all there and of course I took offence to that” . The relationship between doctor and patient was fragile, the relationship between partners was tested.

Finally, the day came when inconspicuous detail began to emerge as vivid and visible:

And then I got up one morning and I said to [their partner], “I’ll make you some eggs,” and I didn’t know how to make the eggs and I was just standing there with a pan in my hand and put some butter in it and I didn’t know what else to put in it to make eggs, and [they] said, “That’s it,” turned off the stove, got me dressed and threw me in the car and away we went straight up to the doctors and that’s when I landed up in the hospital, that same day . . . [the doctor] said, “Go to hospital.” . . . she just said, “I don’t think it’s Alzheimers at all.” (CMR17, int2, p.5)

Not only was the participant embattled but the doctor may very well have been too. Becoming embattled is noted by the short sentences used and the tone of the dialogue. The participants constant social/family issues contributed to her becoming embattled, layered over the deterioration of her physical condition. This sequence of excerpts highlights numerous issues. In terms of becoming embattled it shows how the participant reacted emotionally and behaviourally as her equilibrium was destabilised, in part due to her slow bleeding cerebral aneurysm. The participant was tiring of constantly having to work hard at making inconspicuous detail clearer to her doctor. The excerpts show how relationships were strained between doctor and patient; a partnership tested.

The next subtheme, evolving illness, shows how participants reflected upon their time of crisis leading to admission to hospital and during the initial time of their hospitalisation. From their

reflections, participants tried to make sense of some of the experiences they had had, coming to terms with more conspicuous illness.

### 6.4.3 Evolving illness

As soon as the disequilibrium emerged and no longer could be ignored, or inconspicuous detail began to become conspicuous, participants began to recognise an evolving illness. Therefore, the theme evolving illness, signifies a time of frenetic activity committed to revealing the in/conspicuous detail of illness, plus reflects upon the events that have brought them to this point of living with illness.

The following excerpt shows how participant 23 was aware of evolving illness even if the in/conspicuous detail of his illness were not indicative of cardiac pain:

Although I've got a problem, overall, my health, I think, is not, you know, it's in that middle, not brilliant and it's not dire straits. Although I suppose a heart attack is pretty deadly, although at the time, I didn't think I was having a heart attack then, but I knew there was something wrong. (CNB23, int1, p.2)

Initially the participant is stoic and still ignores his diagnosis, he reconsiders "Although I suppose. . .", explaining it's not "brilliant" nor "dire straits". The participant reflected "I suppose a heart attack is pretty deadly". The conspicuous detail of evolving illness is identified as a "heart attack". Gadamer has written "a disturbance which can no longer be ignored" (1993/1996, p. 55), a diagnosis such as a myocardial infarction can no longer be ignored, particularly as the participant explained "there was something wrong".

A further participant demonstrated the theme evolving illness. When we first met before his heart surgery he was dealing with the enormity of his evolving illness, therefore also becoming embattled as a reaction to the news of requiring surgery and revealing the inconspicuous detail of his high blood glucose (later diagnosed as type 2 diabetes). When asked how he felt about having high blood glucose, he replied:

I knew I had hypertension . . . I've been treated for that by the previous GPs [general practitioners] and Doctors. I knew my lifestyle or eating habits were not very good. So, I knew my cholesterol was high. In turn that may cause glucose or sugar levels to be high as well. I don't know what the numbers were, but I knew they'd be high. . . I don't know if I've been tested for it [diabetes] or not . . . as far as I know right now, that yes, I don't have diabetes. (CRY30, int1, p.1)

This excerpt came from the first interview, a week after he went home, when he noticeably had had time to think about diagnoses and treatments as part of evolving illness. The participant

began with likely starting points when his illness may have evolved. He then described an important contributing factor to his evolving illness, his diet. He also knew that inconspicuous details were considered such as his cholesterol level. He had a lot of insight into his evolving illness but explained off tape (note made in reflective account, June 2010) that he had disregarded all the signals (hypertension). In the final line there is a sense that there is hope he does not have diabetes, the reflection is positive.

The subthemes for the first major theme invisible disequilibrium have been discussed (Sections 6.4.1-6.4.3). The subthemes reviewed are about the inconspicuous detail evolving as illness. The second major theme dialogue as caring is supported by three subthemes: restorative dialogue, caring and (re)constructing illness. These three subthemes represent recurring ideas from interviews that relate to the notion of care, by others and caring for the self.

## **6.5 Dialogue as caring**

The major theme, dialogue as caring, relates to how participants interpreted their experiences; they expressed the meaning of living with illness so far. The concept of dialogue is integral to these three subthemes, meaning there is communication between the participant and others (health professionals, family or significant others), and that participants described how communication is successful at various levels. A second notion, caring, is also central to the three subthemes. Caring and dialogue together signify how participants were motivated and then undertook various activities to counter or support illness. Jonsdottir et al. wrote “the evolving dialogue itself represents change as action in people’s lives” (2004, p. 245). What is of interest here is the evolving dialogue between participant and others, and the dialogue they have with themselves. In the interviews, participants offered details of therapeutic relationships which in turn illustrated care and caring.

The interviews, could at times, be an occasion to clarify detail of medical or nursing management, the dialogue became a ‘dialogue as caring’ in itself. An example follows:

Maybe once a week if that [they use GTN]. Yeah, when I do get it [pain] I notice that when I use it [GTN spray] straight away now it [pain] goes away where before it didn’t because it [GTN spray] had expired. The nurse said I may as well spray water in to my mouth [if the GTN has expired]. I carry one with me all the time. I have one in my work Ute, one in my car. One at work, and one at home, and one in my golf bag. (CPK31, int2, p1-2)

This interview excerpt is an example of ‘dialogue as caring’ where the participant reflects, largely speaks with himself to confirm a point of medication use. The use of medications is a

significant topic in the theme dialogue as caring as will become evident in the three subthemes restorative dialogue, caring and (re)constructing illness. The three subthemes are thus described in more detail.

### 6.5.1 Restorative dialogue

Being involved in a restorative dialogue, participants sought to reveal the in/conspicuous detail of illness. The participants engaged with various people to discuss their concerns about their health or illness. They talked with their families, significant others, friends, and with health professionals. In discussions with others, the dialogue had some sense of restoration and motivation, in turn the participant describing how they became (or did not) more motivated about living with illness.

The dialogues with participants revealed a variety of health activities which carried with them some risk. These risks were weighed up by participants as patients, and some participants were willing to take risks to aggravate illness. For example, participants talked about drinking alcohol, or consuming high amounts of salt and butter. Stating what they had done is dialogue, and expressing some motivation to alter the behaviour is a restorative dialogue. Participants talked about what they as patients knew they needed to do (Jonsdottir, et al., 2004), rather than what the nurse (or other health professional) believed the patient needed to do.

The following excerpt is from interview 2 with participant 6 who was found to have type 2 diabetes:

Participant: I was very disappointed when I was told I had diabetes. Well, you know I had that original test where I had to fast and all that for two hours and drink that very sweet drink, and that's when they told me, and I really was quite disappointed. I thought I had enough [illness] without that . . . but you see I've just had that other test [HbA1c], and only about 6 – that's not too bad, is it?

*Kim: Have you discussed this at all with your doctor?*

. . . the nurse from the doctor's surgery rang and said that the results had come back and I was type 2 diabetes.

*Do you know what that means?*

Well, I cut back on sugar. I went to the supermarket [with a group of people with diabetes and a dietician]. They have a big group that goes and they discuss things on the shelves and it shows you where to look for the sugar and things. I found that quite interesting. I've got a lot of literature about it. I've got to look after my feet [reflective account mentions socks were taken off and feet exposed and briefly discussed]. (CIM6, int2, p.5-6)

This part of the interview was taken to be a restorative dialogue because of the sudden way the diagnosis was announced in the conversation, there was a need to speak to someone (the

interviewer this time) about the in/conspicuous detail of her new diagnosis even though they had spoken at length with the practice nurse. The dialogue was a place to linger and learn. There was a fleeting reference to comorbidity “I thought I had enough [illness]”, the opportunity to expand upon this was not taken.

The participant briefly discussed some detail about foot care for those people with diabetes, as she brought out the extensive literature she had collected since diagnosis:

It’s [leaflets about diabetes] floating around in the cupboard. That might be it [the information on foot care]. [All the information is] from the nurse at the doctor’s surgery. Well, I’ve read it all. . . the nurse gave me all this – tips for coping with [a variety of issues as well as foot care]. (CIM, int2, p.6)

This excerpt is a good example of how the participant confirmed her diagnosis in the interview. She made inconspicuous detail conspicuous by her commenting on the need to look after her feet to avoid development of peripheral neuropathy. In her confirmation, she also showed she was motivated to work with this new aspect of illness. In stating “I’ve read it all”, the participant determined her desire to absorb new information, she was inquisitive. All of these attributes contribute to a fresh reconstruction of illness by the participant, a need to keep building upon current knowledge.

The above narrative demonstrates an element of restorative dialogue with motivation to learn about their condition. The participant discussed conspicuous detail which she made more overt by entering into restorative dialogues. These dialogues helped her reconstruct an understanding of her illness which included a diagnosis of diabetes.

The next section describes and details the subtheme caring, and how caring intersects with other subthemes, restorative dialogue and (re)constructing illness.

### **6.5.2 Caring**

Caring is concerned with what the participant activates in terms of care and caring. The iterative restorative dialogue represents what participants learn, want to learn and what potentially motivates them to take further steps, caring represents taking responsibility to achieve goals be they ever so small. Returning to participant 6 and her experience of living with a new diagnosis of type 2 diabetes:

That’s one thing that I do worry about; this business of when you get low in sugar and you feel a bit funny. . . that happens to me and I crave something sweet. I don’t care if I don’t eat chocolate . . . I don’t eat ice-cream because of my cholesterol. I had sugar in my tea and coffee and that’s what I really miss . . . and the nurse worked it out that I

was having about five cups of something a day, and that added up to quite a lot of sugar. So, I've cut all that out. I have a biscuit now and again . . . because I feel I need it, but I wouldn't say I had a sweet tooth – not really. I've bought myself some jellybeans and I have one of those if I feel a bit low. (CIM6, int2, p.6-8)

The participant discussed with the practice nurse what to do if she felt hypoglycaemic, hence a restorative dialogue. This is followed by a good example of caring for herself, what she has done to counter the possibility of “I feel a bit low”. The example also shows how restorative dialogue and caring are linked as learning and activating actions that attempt to dispel disequilibrium (as per Gadamer). Inconspicuous detail (hypoglycaemia) has been made overt as a potential conspicuous detail. This is an important aspect of prevention, knowing about risk (not having enough glucose available) and activating strategies to prevent it (having jelly beans to hand), and being aware as it begins to emerge (knowing what feeling “a bit low” feels like).

The above excerpt reveals how hypoglycaemia has become internalised, part of the participant's construction of illness. She described how “I feel a bit low”, describing how a strict equilibrium of sugar needs to be maintained. She further that some sugar is important to her usual functioning “sometimes I have a sweet biscuit, because I feel I need it”. The participant made no reference to how taking a low sugar diet would also affect her cardiovascular disease, hence no specific reference to comorbidity. She has incorporated her new diagnosis of type 2 diabetes into her life and living by making a conscious effort to avoid loss of equilibrium, by focusing on her diet in particular her intake of sugar. There is a sense of ongoing self-assessment, being mindful of how caring for the self would potentially benefit her health.

The subtheme caring refers to the recurring notion of what it was that participants did to instigate care or caring. This involved hearing how participants came to understand the relevance of caring, and how this interpretation is nested in their emerging construction of illness. The following section provides insights of the last subtheme, (re)constructing illness.

### **6.5.3 (Re)constructing illness**

The subtheme, (re)constructing illness, is part of the cyclic nature of ‘dialogue as caring’. The construction of illness is constantly restructured as participants described how they entered into dialogue, learned absorbed and created new meaning. Participants explained they entered into a dialogue and learned to adopt a restorative dialogue. Additionally, cooperating with health professionals or significant others, participants entered into caring options by accessing health services. In doing so, participants made sense of in/conspicuous detail, which in turn contributed to further understanding their life with illness.

Participant 31 discussed his diagnoses:

Participant: They [diagnoses] won't go away I think, I'll just manage [them]. The heart problem's always going to be there. I think the stomach problem will probably always be there as well.

*Kim: And what about your glucose level?*

I didn't think I had a problem with glucose?

*We're hoping that, but you haven't had a [second] blood test yet [to definitively establish diagnosis]. (CPK31,int2, p14)*

After participant 31 was discharged from hospital following his myocardial infarction, he attended a men's health workshop organised by his work place. Reconstructing illness was noted as the participant engaged in restorative dialogue with work colleagues in order to improve his own understanding of illness:

We had a men's health day at work. We had a little Indian lady come in and she talked about prostates and then we had one of our guys stand up and talk about his case and how he got it taken out [his prostate gland] and hearing it from our own work colleagues is good.

And then someone else got up and spoke about diabetes. And then one of our guys got up and spoke about diabetes you know. About things that he was going through and you know he's on injections and things like that. I always wondered why he always had lollies in his truck. And then we had someone else get up about his heart problems that he was having so hearing your own work colleagues stand up and talking about it . . . kind of opens your eyes about it [illness].

And I think after that a lot of guys went in for their prostate cancer [check up].

[The most useful thing was] probably just opening up, hearing it from your own work mates. (CPK31,int2, p.17-19)

The participant was genuinely impressed with the presenters from his work 'men's health day', he seemed receptive to being motivated to be proactive about his health. The dialogue with his workmates seemed to bring his own health into a sharper perspective, using the experiences of others to consolidate his own construction of illness "kind of opens your eyes about it [illness]". Making meaning, as constructing illness, evolves from many sources, and participant 31 has exemplified one important source, listening and talking with work colleagues or peers.

This completes the exploration of subthemes for the second major theme dialogue, caring. All three subthemes reviewed highlight how participants described the more positive attributes of illness as a dialogue as caring. Their dialogue involved identifying the motivation to alter lifestyles by entering a restorative dialogue. Participants also explained what they actually did in terms of caring for themselves or alternately what care participants received from other people and what health services were accessed.

## 6.6 Conclusion

This chapter has presented the overall thematic framework that was synthesised from interview data. The aim of the framework is to visually and abstractly demonstrate how the themes were derived and provide supporting evidence from the interviews. The framework has an overarching theme as inconspicuous and conspicuous detail of complex illness. The detail of illness unfolds as two major themes invisible disequilibrium and a dialogue as caring. The in/conspicuous detail of invisible disequilibrium is characterised by: losing equilibrium of the body, becoming embattled as disequilibrium progresses, and living with evolving illness. During a dialogue as caring, detail are rendered conspicuous and/or inconspicuous at turning points: during restorative dialogue as motivator, caring as per plan, and experiences of caring contributing to a (re)construction of illness.

A fuller staging of the themes is presented in subsequent Chapters 7 and 8. The major theme invisible disequilibrium is described in more detail in Chapter 7, giving more examples of what participants said about the in/conspicuous detail thereof. Chapter 8 details more about the major theme dialogue as caring and highlights constructions of illness as people engage in activities of care and experience caring. Both Chapters 7 and 8 provide some interpretation of the participants' experiences from the researcher's perspective, adding a further layer of synthesis to what the participants have recounted in their interviews.

## Chapter 7

### Interpretive findings: Invisible disequilibrium

#### 7.1 Introduction

This chapter further progresses the participants' experiences by reflecting upon, describing and interpreting what the inconspicuous and conspicuous detail of invisible disequilibrium could mean for the participants with CVD and prediabetes. This involves drawing upon the theoretical threads central to this thesis. The first theoretical strand is Gadamer's philosophical writing as pertaining to health. Merleau-Ponty's philosophical perspective is also drawn upon to reveal and interpret the experiences of the participants in accordance with interpretivism.

The findings in this chapter reinforce aspects of the whole story as stated in Chapter 6, wherein interpretation sits alongside description, in keeping with the methodology of this research, interpretive description. The subthemes reveal a number of clustered notions which are common across interviews. These clustered notions were found to be embedded hence the use of the term embedded subtheme to indicate the visible or a conspicuous detail running throughout a subtheme. The embedded subtheme came about during the course of extensive iterative reading and reflection upon the interview data. The embedded subthemes are integral to understanding and interpreting particular subthemes and major themes, capturing a visible or tangible conception of the subtheme to which it is matched.

The major theme invisible disequilibrium is described in more depth and also interprets what meaning can be gleaned from the interviews. The subtheme losing equilibrium (section 7.2.1) is exemplified and discussed by using a number of interview excerpts. The second subtheme becoming embattled (section 7.2.2) is looked at in some detail, with three embedded subthemes humour alleviating embattlement (section 7.2.2.1), contemplating surgery (section 7.2.2.2) and delaying seeking advice (section 7.2.2.3). The subtheme evolving illness (section 7.2.3) intuitively provided further embedded subthemes: perceptions of social constructions (section 7.2.3.1), reliving a disarray of events (section 7.2.3.2), experience of the living body (section 7.2.3.3), awareness of pain and the living body (section 7.2.3.4) and illness evolves by remaking life (section 7.2.3.5). The in/conspicuous detail of these subthemes and embedded subthemes are woven into the presentation of these findings.

## 7.2 Invisible disequilibrium

The major theme invisible disequilibrium is represented by subthemes: losing equilibrium becoming embattled and evolving illness. This theme represents an amalgam of experiences that contributed to participants constructing an understanding of these experiences of a myocardial infarction or angina. All participants described how their life reflected a build-up of signs and symptoms before hospitalisation. There was a growing consciousness of disequilibrium. This awareness was augmented by the disarray of miscommunication and/or testing of relationships. Participants all described some level of disarray as they became embattled. They reflected upon these experiences to reveal inconspicuous or more conspicuous detail as illness evolved.

Detail here are the elements of living with illness and health as described in Section 6.3, details which may or may not have been evident to the participant before their myocardial infarction. As the participant lost equilibrium detail became more conspicuous. Gadamer writes about re-establishing equilibrium in the same way as equilibrium is lost, “there is no continuous and perceptible transition from one to the other, but rather a sudden change of state” (Gadamer, 1993/1996, p. 36). Just when equilibrium seems steady or stable, the balance is suddenly tipped into a state of disequilibrium.

### 7.2.1 Losing equilibrium

The subtheme losing equilibrium, demonstrates the in/conspicuous nature of details that contributes to complex illness. The unobtrusiveness of health, or not noticing state of well-being (Gadamer, 1993/1996) suggests inconspicuous detail are constant. People participating in this doctoral research indirectly made reference to their well-being rather than direct statements about their health. In answering the question: “In general would you say your health is excellent, very good, good, fair or poor?”, Participant 7 answered:

I’m permanently tired, no energy, sleep badly . . . feel bad; just don’t feel well most of the time. I suspect that it’s had something to do with my heart for quite some time because I’m fully expecting something else to narrow for a while in there [indicating his chest] . . . always, always waiting for it. (CRW7, int1, p.1)

The conspicuous detail focuses on well-being. The subtext is the expectation of inconspicuous detail to come to light in future. This participant awaits further obstruction of coronary arteries and therefore awaits prospective possibilities such as further coronary artery bypass grafting. His well-being is diminished by the dwelling upon inconspicuous detail of illness he expects to experience. Well-being refers to a positive “conceptualisation of health: feeling healthy, happy or doing well in life” (Liamputtong, Fanany, & Verrinder, 2012, p. 4).

Some participants were continuously experiencing disequilibrium. Participant 13 described himself as having chest pain while on the way to interview 1. The building that we were meeting in for our interview was up a hill. I had not met this participant before and found he was experiencing chest pain as he walked into the hospital building. (The assistance of a passing doctor was immediately enlisted to relieve the chest pain!). Later the participant was asked if he still had chest pain:

*Kim: Are you at the moment experiencing some [chest pain]?*

Participant: Not really, not as I know it, the angina is a terrible chest pain and just to walk up here I just feel I was running out of steam and was getting a chest pain but not as I know it. . . I like to think it wasn't angina really. . . its right in the [pointing to chest centre].

[In the past] it seems to be more this [right] side and down the arm. I thought I'd use my spray and sit down for a minute which I did and it all came back to normal within five minutes. . . this is the first time I have had it since the procedure [angiogram] a week ago. (CDW13, int1, p.2-3)

The participant told me “not as I know it” in his first line of the quote which indicated he thought his state of equilibrium was potentially questionable, he was unsure, his confidence was undermined. Added to this he lived on his own, his wife was in care, so support was not immediately available to him. This was a difficult time for him as he sought reassurance concerning his ability to make judgements about his chest pain. He sought assurance as he began to reconstruct his understanding of his illness.

The indecision about their condition, was a pattern noted from a number of interviews. Some participants rang family or significant others for advice as disequilibrium emerged. The following excerpt from participant 22's interview, whose morning sleep in was interrupted with a new sensation in his chest:

[I] went back to bed, read the paper for a wee while, went back to sleep for a while, which is unusual. I felt a bit cold actually, so I tucked under and went back to sleep, and then woke up and started reading the paper, and that's when I started to feel a sort of a sensation I wasn't used to, which was sort of like something was coming up my torso. It was a feeling – wouldn't even call it pressure at that stage. It was like something moving up my body, and it wasn't painful. It was discomforting, and then I started hot sweat, cold sweat fairly quickly. So, called my daughter and she called the ambulance straight away. (CGB22, int1, p2)

This was a recurring event for some participants in this study; the participant was not sure what was happening, often describing a new sensation but no real pain. Frequently family members were enlisted to help ascertain if the events were worthy of a trip to a hospital emergency department. The inconspicuous detail was unexplainable and therefore frightening. Another example to support this follows:

I got up [during the night] and I thought “you’ve got a bit of pain”, then I thought “that will go away”, just got a bit of indigestion and then I made a cup of tea and I drank that and it got worse and then [his wife] came out and said “is something wrong with you” I said “I’ve got a pain in the chest”, “have you?” she says, and she rang up [the ambulance]. (CRM27, int1, p.8)

A pattern emerged here, participant 27 and 22 both consulted family members or significant others they trusted. Even though participant 27 had pain he still consulted his wife to confirm that a trip to the local hospital was necessary. The participant was asking another to help make meaning of the situation, a form of co-creating meaning. Often, as was the case for these two participants and other participant experiences not included here, the significant other made the phone call, they recognised the gravity of the situation.

Some participants explained how their loss of equilibrium meant they also lost track of time, indeed they were unconscious. Participant 25 recounted his experience:

I got up to put the jug on and then I started feeling a little bit dizzy, nausea, I just walked straight out in to the bathroom, bent over the toilet, wasn’t sick, I was doing all this slowly mind you, everything was starting to spin slowly and I was feeling no pain . . . I remember bits and pieces, ‘stay awake’, ‘open your eyes’, ‘hold my hand’, ‘squeeze my hand’, somebody says they would get the defibrillator, it was like my brain was in a jelly you know and everything was just floating around, not making much sense. (CAH25, int1, p.2)

The participant knew he was gradually losing consciousness, the loss of equilibrium was both a physical and mental change, details both conspicuous and inconspicuous. The initial loss of equilibrium started with the onset of dizziness and nausea. This quickly deteriorated to a full collapse with little recollection of detail of the incident. Like many other people who experience unconsciousness, his state meant he had lost awareness of conspicuous detail that led to his urgent hospitalisation.

Other participants experienced far less change, less disturbance of equilibrium, less pain, which made it difficult for them to assess what was happening. Some experienced far less pain but became aware of a different sensation (see CGB22, int1, p2, previous page). Other participants had cardiac pain muddled with indigestion or other old chest injuries as participant 17 did:

I had a fall on my [side] . . .with the motor mower and then I had all this pain coming around my tummy which they thought was gall stones, I went to the doctors the next day and she [the doctor] said she thought I had a cracked rib [from the accident, nothing related to cardiac pain]. (CMR17, int1, p.1)

Pain is distorted so its origin was less clear. What becomes more distinct was how detail was inconspicuous even though disequilibrium progressed. Disequilibrium also represented as breathlessness. Some experienced more breathlessness than pain as participant 4 explained:

The breathless got quite severe, I mean our letterbox from the house to the gate I couldn't make it. During the day it was alright when I had a couple of puffs [of GTN]. I saw [the doctor] and that was when it really started [events toward his admission to the Cardiac Unit].(CEWH4, int1, p.3)

Participant 4 experienced an acute infarction as well as congestive heart failure; he explained that his significant experience was that of breathlessness. The excerpts demonstrate the unique nature of events that brought people to hospital for investigation of disequilibrium which was unfathomable at the time.

A concept that was indirectly referred to by participants was that of risk. Risk contributed to the gradual loss of equilibrium, as participants spoke of their family history revealing previous generations with cardiovascular disease. Other participants recalled their lifestyle being incompatible with healthy living and again contributing to CVD. They had made risky choices, they had engaged in risky activities as a preference, as a social construction of culture (Lupton, 1999, p. 37). Participant 21 gives examples of both conspicuous and less conspicuous risk:

Participant: I was aware of the elevated cholesterol especially with my dad dying very early [he died at 49 of a myocardial infarction] I was getting check ups every 18 months to two years. Other than keeping an eye on it [cholesterol] it wasn't off the scale, it was elevated especially the LDL, the bad cholesterol was always elevated. And we were just trying to keep an eye on that but I guess we missed the opportunity there. [His father dying young] it's always been on my mind you know obviously the family history so I've always been aware of that and I've been conscious of diet and exercise, I wouldn't say it worried me but it's always been there that I knew family history plays a big part. (CAG21, int2, p.4)

*Kim: What other lifestyle changes have you made between you know this business last year and today?*

Participant: I guess dietary just the little tweaks more than anything; I think my diet was probably actually quite good in hindsight. Like any New Zealand male you know, I used to enjoy having a few beers, I guess if there's any alcohol now it's just maybe a glass of red wine. I mean very occasionally I have a beer, yeah it's one thing I pretty much cut out at least 80 to 90% now. I guess we weren't massive on takeaways but used to have it like once a week. Now I don't, I just don't, if we have takeaways I might get a piece of fish and have some vegetables, I don't touch fries or chips any more at all. . .even at work on a Friday some people bake a cake, I say no thanks. I guess I used to have a bit of a sweet tooth but I don't touch the stuff any more. . .you look at food quite differently. It's almost like it's a good trigger in your mind now. I mean I think I would have ranked pretty highly on diet because I was always aware of dad's condition. I think I've gone up to the next level where just a lot more conscious of any treats really. I've really cut back. (CAG21, int2, p.11-12)

This large quote shows how participant 21 was aware of the inconspicuous detail of family history and how this may have effected his own health. He has made considerable changes to his lifestyle, changes to conspicuous detail such as: alcohol consumption, what he eats, dietary choices, exercising (although only mentioned), making conscious choices about food (e.g. in the work environment when food is offered). This quote is placed here at the end of the section

addressing losing equilibrium because the participant understands that his acute event (myocardial infarction like his father had), his imbalance is partly due to unavoidable risk (family history of CVD) and avoidable risk (watching choices in food consumption and regularity of exercise). His understanding of CVD is culturally based in family and social environments, entrenched in medicalised risk. A more detailed discussion about risk with reference to this quote is found later in Chapter 9.

The subtheme losing equilibrium signifies those experiences that describe a dissipation of energy, a breaching of the normal status quo, equilibrium is disturbed. The inconspicuous detail becomes more conspicuous, sometimes with no tangible explanation other than “something was wrong” (CAG20, int1, p.1). The following subtheme describes and begins to give meaning to how participants coped with the emotional and psychosocial disarray that they experienced.

### **7.2.2 Becoming embattled**

This subtheme is multifaceted and dynamic as people’s reactions were diverse. The theme involves the emotional or subjective outbursts that accompany those who are losing equilibrium. The following excerpt of an interview is that of a participant with no previous cardiac anomaly. He was discharged home before he was interviewed, thirteen days later at the outpatient department. He described himself as he gradually became embattled:

When I went to the treadmill, my legs gave out and short of breath, and they gave me oxygen there. I didn’t have chest pain, me legs was, I couldn’t do it properly, [the doctor] said “stand up and do it”, and I tried but, I just couldn’t, my daughter was with me, she laughed, you know, she said “you looked horrible” and she said how easy it is, I said well it might be but . . . I just couldn’t grasp it at all. (CFP11, int1, p.4)

The first two lines express how the participant was losing equilibrium, he articulated the loss of power of his legs, and an attempt was made to restore physical equilibrium (with oxygen). The participant reacted sensitively to his daughter and is distressed at his lack of ability to master the treadmill. This subtheme is about falling apart, permitting this to occur before any sense can be made of experiences. It seemed consistent that there was a pattern of becoming embattled, for however long, and that this embattlement had a turning point, something happened from which, as uncomfortable as it was, participants constructed some meaning from their experiences. These moments of inconspicuous detail gradually became conspicuous or even understandable. When the participant gathered their thoughts, most were able to comprehend how their disequilibrium occurred, and with this understanding came a construct of experiential knowledge. To begin to construct an understanding of illness, participants were placed in uncomfortable situations in order to further experience and interpret illness.

The same participant (11) had had an angioplasty, which was an important step for him in making his cardiac condition 'visible', literally by looking at the x-ray screen and watching the stent being put into his stenosed coronary artery:

I was lying down and needed to turn my head over onto my left side and then I just looked up and I could see my heart [on the x-ray screen], I guessed it was my heart, I said "is that my heart?", he [the cardiologist] said "yes I'm just putting the first stent in" and I won't lie and he put it [the stent] in [tone of amazement]. (CFP11, int1, p.5)

In this excerpt the participant's construction of illness is evolving due to the observation he made of his heart as described above in the excerpt. Participant 11 was interviewed for the first time a week after he was discharged. Over the course of our interview the participant talked about his difficulty in mastering the treadmill (CFP11, int1, p.4) and as above reflected on the ingenuity of the angioplasty (CFP11, int1, p.5) both points representing the major theme invisible disequilibrium. During the time of discharge till when he was interviewed, he will conceivably have had time to reflect upon his experiences and have begun to make sense of his recollections. An evolving construction of illness was well underway by the time participant 11 was first interviewed.

An additional participant with no cardiac history, interviewed fourteen days after discharge having had CABG<sup>4</sup>, seemed much calmer. He was very anxious at the time he was approached for participation in hospital. When he agreed to participate I suggested that perhaps I interview him after surgery before he went home. I caught up with him after his CABG surgery in the ward but found he was exhausted, so a further decision was made to interview him when he had gone home. He explained he was recovering well, and seemed calmer. When asked what had sent him to the after-hours medical centre he replied:

Previous to that night [of admission] I had some chest pains, cold sweat, pins and needles in both of my arms and upper chest, which lasted for about 10 – 15 minutes. Once [the pain had] gone, the wife just persuaded me to go get checked in the [local] emergency after-hour service, and once they checked it with an ECG they whipped me off to the local hospital for further diagnosis. I was feeling alright, like normal – no pains, no nothing. They just said after they hooked me up to the machines, they noticed there were some irregularities and I may have had heart failure in the past. That's why they said you'd better go to the hospital and get it checked out. (CRY30, int1, p.1)

Participant 30 gave a very clear account of the events leading up to his admission, there was very little emotion, he was very matter of fact. This is in complete contrast to an attempt made to interview him before he was discharged home. The reflective account reads:

Mr X is in still, I see him about possible participation. He talks very quickly, almost manic. Very anxious still. The [nursing] staff tell me he is very sleep deprived. Even a minimum of questions could make interviewing difficult, will make another time to interview him. (Reflective Account, 20 May 2010)

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<sup>4</sup> Coronary artery bypass graft(ing).

As a nurse the right choice was made, not to trouble the participant with an interview about his condition when already exhausted. The therapeutic option was to postpone the interview.

Sometimes the emotion of a conversation is not really overt; of itself emotion can be an inconspicuous detail. Mr X is a 79 year old man who had just come back from visiting his sister in Europe where he too was born. He had just arrived back in New Zealand a week earlier before this particular hospitalisation. The reflective account mentions he looked tense and emotionally he seemed surprised to have had a myocardial infarction, he last had one 25 years ago. He does have a strong family history of cardiovascular disease on his mother's side. Mr X lives alone with no family of his own but has a brother and his extended family living close by. The emotion in this conversation was difficult to pinpoint. One could feel a strain; one became aware that Mr X was tense. Although not outwardly embattled, he was holding great tension within. He described why he came to hospital:

While I was having breakfast I had angina, what I thought was angina attacks again so I used the spray [GTN] wouldn't go away so I used it about three times and it still wouldn't go away, it was the pain just got worse, my arms got heavier so I rang 111. I [felt] sweaty and out of breath and I was could hardly move I was holding the phone and of course the girl in the ambulance talked to me till the ambulance arrived. (CHS5, int1, p.3-4)

The same participant was asked how he felt about being in hospital, he answered the following:  
Well not too happy naturally. This time around I thought with the angioplasty they could fix it. They couldn't put a stent in where my narrowings are. So what happens next is the only other option is open heart surgery. (CHS5, int1, p.7)

His answers were clipped and a little stoic. It was only when we discussed his favourite food that he had been eating in Europe that he perked up, and said that his sister had been spoiling him. Not only was it useful to strike an interest (in this case food, and it should be added here he is slim!), but it occurred to me that he may be home sick, even though he had made New Zealand his permanent home. This may not be the most demonstrative excerpt of a person with illness becoming embattled, unpacking the sources of tension have helped to come to some likely reason for the lack of emotion sensed in our conversations. Participant 5 may very well have been concerned about facing mortality, on his own, away from family members in Europe.

### **7.2.2.1 Humour alleviating embattlement**

The following excerpt shows how embattlement may include humour to disperse the emotional severity of events. Participant 13 was interviewed nine days after he was discharged, and his

admission was not the first for his condition. He recounted events in the local emergency department:

*Kim: And what sort of procedure did you have [on admission]?*

Participant: Well they stop your heart and restarted it again . . . defibrillation. They told me what they [the medical staff in the Emergency department] were going to do [cardioversion], I remember the whole team coming in including the cleaning lady to see it being done and she had a mop with her. All the juniors and everything including the manager of the [Emergency department] came in. No they knock you out for that . . . they stop your heart for 10 seconds and reboot it. Sometimes your computer plays up, you turn it off for 12 seconds and it comes back, that's what they did to me. (CDW13, int1, p.1)

This recollection of events seemed comical, but he was quite sure upon questioning that the cleaning woman was present. This quote demonstrates embattlement in that humour is used to diffuse the enormity of the situation. There is also a pride in the success of the procedure, which unfortunately was coupled with some ischaemia hence his involvement in this study. A state of equilibrium is restored, likewise the disharmony of conspicuous detail are restored. The above quote portrays a metaphor indicating an evolving construction of illness.

Participant 2 used humour to describe the events that led to his admission to hospital. It was at this time that conspicuous detail was mitigated with a quirky comment, which seems to reduce the otherwise dominant effect of "distress". Participant 2 explains:

Approximately 8.30 on Saturday morning I was lying in bed and I started to get chest pains. With my considerable degree of expertise I felt that I was probably having a heart attack coming on so I thought it was important to remain calm therefore I had a glass of orange juice and a cigarette . . . then things started to happen very quickly, by 9 o'clock I managed to get myself upstairs unlock my front door, get my grab bag out of the office and call the ambulance. At that stage I was getting extremely distressed, the 111 operator kept me on the phone and kept giving me crap like I was doing very well when I knew I was dying, or it felt that way. (CPC2, int1, p.3)

This interview excerpt is a vivid account of the conspicuous detail 'pain' making the invisible disequilibrium more conspicuous. Again humour was used to tone down an otherwise adverse experience to veil emotions such as fear ("it was important to remain calm therefore I had a glass of orange juice and a cigarette") and anger ("I was getting extremely distressed") the conversation became humorous because it dared to tell the truth (Didion, 2005). The very last comment "when I knew I was dying" seems uncharacteristically sombre which brings the whole conversation back to reality, and one might ask was there a fear of dying alone? In these moments of self-awareness, the participant was crystal clear about the possible trajectory of events that may occur.

A further point worth considering from this interview excerpt was how organised this participant was. He lived alone so needed to have a plan for these situations. "Not

uncommonly, ill individuals organise their activities carefully and methodically without full awareness of why they make certain plans and choices” (Charmaz, 1991, p. 138). It is not clear why participant 2 was so organised (grab bag always ready). Having gone through previous episodes of chest pain may have galvanised the participant to be prepared to leave home in a hurry, to hasten an about-face as another brush with death supervened. Even though periods of embattlement are traumatic they can be a time of learning. Having a bag ready may be behaviour developed through experiential learning, established through personal experience or as told by others having similar experiences. Together, this adds to an emerging understanding of illness.

### **7.2.2.2 Contemplating surgery**

Six participants had angiograms that indicated they needed urgent coronary artery bypass grafts. The time between alerting them of the angiogram result and going for surgery was a period to contemplate the immediate future. Without exception, all six participants stated they had some anxiety of the prospective surgery either on tape or in passing conversation. One participant spoke of this indirectly:

He is a lovely guy [the new partner] . . . his wife died about ten years ago and I was a bit worried that all this would bring it all back for him. (CJG16, int1, p.9)

The participant’s own anxiety (which she expressed on several occasions off tape) was directed at her new partner whose previous wife has died. The participant was not only anxious about her surgery but also about how it may affect her new relationship.

Embattlement as fear found many forms throughout the interviews. Fear was sometimes channelled into denial of disease or conspicuous detail:

How I feel right now is that they are going to open me up and find there is nothing wrong . . . that is how I feel. I know I am dreaming, I feel good because I’m on all this medication so of course I feel good. (CJG16, int1, p.16)

Participant 16 had four successful coronary artery bypass grafts. After surgery she was visibly relieved all had proceeded so well. Denial had been replaced with a reassurance that the surgery had been necessary.

Discussions about surgery with friends or family were a further common thread found in the interviews. One participant admitted to hospital with unstable angina had an arteriogram showing that he had some atherosclerosis but not sufficient to require surgery at that point. He did have sufficient angina to potentially warrant surgery in future and this was part of our

conversation. He explained how he and a friend had contemplated the need for surgery and made the following observation:

I've got a friend and he's had a triple bypass he said he went in there with a heart attack. He's not had one little bit of pain whatsoever, nothing. And he's looked at me and he knows what I've had done and he says "you'll have these pains where you have [had] to go back in and just get checked, he says, you go in there and you come home again and he says he's had nothing. And he says "do you think you should have one?" I don't want one for the sake of having one, but if it's a scenario where it's going to make a big difference, [then] yes. (CNB23, int1, p.18)

The excerpt demonstrates some element of disappointment that his condition was not severe enough, that detail was not sufficiently conspicuous to warrant surgery. Participant 23 expressed a point made by several other participants, asking would he ever need to have CABG surgery. This relates well to the statement made by participant 7 (CRW7, int1, p.1) earlier in section 7.2.2, that participants were waiting for coronary artery disease to develop so surgery would become essential. Even though participant 23 did not require surgery he kept this detail in the present and future for himself as he continued to live with unstable angina. In the excerpt the participant's insight did not differentiate who requires surgery and who does not. He had angina which does not usually indicate surgery via the public system. Here the participant contemplated surgery as curative of his angina, when often it may but diminish signs and symptoms and even this may not always be successful.

The embedded subtheme, embattlement: contemplating surgery, is a pattern that was noted while reading interview data, remaining mindful of surgical interventions. The whole aspect of yet another level of intervention i.e. requiring surgery was not necessarily in the thoughts of participants as they were admitted to hospital with inconspicuous or conspicuous detail. For some participants delaying hospitalisation was about delaying the announcement of bad news as described in the next section.

### **7.2.2.3 Delaying seeking advice**

Participants delayed making decisions to take action upon their invisible disequilibrium. This was a shared detail found in participant interviews. Some participants were tardy as the experience was new to them; they considered advice but were unclear as to when they should access emergency services. Other participants delayed going to hospital because they had been through the experience before and may have hoped delaying visitation to a hospital because aigns or symptoms would subside. One participant conveyed their denial, that the pain or discomfort they were feeling would probably abate:

I sat for three days thinking it would go away and then I got up on the Wednesday morning and I thought I would be normal; I'll go to the Supermarket. I got as far as almost being totally dressed and face on and it [the pain] started. I'd gone to the GP [general practitioner] the day before yesterday. I'd gone to the GP because I'd had problems, didn't quite know what to do and she stuck me in an ambulance and sent me straight here. (CDM10, int1, p.4-5)

Participant 10 has a history of ischaemic heart disease, had been hospitalised before with unstable angina, and was interviewed in hospital before discharge. This participant seemed disappointed that she was hospitalised yet again for the same condition. As detail became more conspicuous hospitalisation seemed inevitable, when perhaps the participant had hoped to avoid hospitalisation. This study has shown evidence of numerous reasons why participants delayed seeking advice about their illness: no diagnosis was linked to pain or altered sensation (CDP20, int1,p.1), self-diagnosis was incorrect (CDJ26, int1, p.1), uncertainty of genuine diagnosis (CDP20, int1, p.1&2), pain would subside (CDM10, int1, p.4), disbelief the participant was having a myocardial infarction (CSC8, int1, p.3&4), fear (CDJ26, int1, p.5), and regular doctor was unavailable to see the participant (CDJ26, int1, p.5). All these possibilities are mulled over as the participant tried to judge if their conspicuous detail warranted the ultimate of attention i.e. a trip to the emergency department.

Any state of embattlement was a time when participants were testing themselves and those people immediately around them. The examples presented illustrate the variety of reactions to the circumstances that participants found themselves in. The detail of illness was emerging, becoming conspicuous.

The following section focuses on participants reflecting on how the detail of illness became in/conspicuous. This has been recognised as a process of evolving illness, as participants amass understanding about their condition from their experiences.

### **7.2.3 Evolving illness**

For most participants there was a period when they were able to take stock of their condition and reflect upon how it affected their lives. This theme finds the participant pensive about the phenomenon of illness. Often observations were quite humble such as “[I] was very lucky. . .” (CEH4, int1, p.4) recognising that their life was changing because of their illness.

An illustration of evolving illness was found in the interview data of a participant waiting to have an angiogram after his admission for unstable angina. He and I talked the evening before his angiogram, discussing what an angiogram was and what it could tell him:

I guess thinking as you talked about [having an angiogram], now I was reflecting on my normal life and in a way discounting this as a bit of an aberration. Well in that sense and say well ok we'll get over this and off we go again. I may have a rude shock in store for me I don't know but we will cope with that when it arrives. (CDH18, int1, p.6)

There is the binary, yesterday was his normal life, and today is an aberration. Adding to this tomorrow is his new normal life. He seemed accepting of this turn of events holding on to his normal life, as that was what he knew. This participant seemed philosophical about the events past (we'll get over this) and ahead of him (off we go again), accepting that there would be further aberration (may have a rude shock in store), even if detail was inconspicuous or not (we will cope with that). He expressed "this" a great deal. "This" was not clear to him yet; it was an oddity rather than the norm.

Participant 18 was interviewed in hospital; he did have a prior admission for a myocardial infarction and had recovered from prostate cancer hence ill health had not escaped him. He was ponderous about his current admission and how this fitted with the past. His construction of illness was dominated by his prior "normal life", the idea that further illness may be evolving was just beginning. Unfortunately his angiogram showed diffuse disease so it was not possible to put in stents; his condition was only manageable with medications and care with lifestyle choices.

Participant 7 was also interviewed in hospital, having recovered fully from Hodgkin's lymphoma which he had had 20 years ago. He also had a history of cardiovascular disease, having already had CABG ten years ago. He was reflective about his current hospitalisation:

Well I have not an uncanny ability to be two people at the same time, I can observe myself which is quite disconcerting sometimes so even though I am sitting down there at the bottom of the well I'm also sitting at the top with the handle ready to wind myself up (CRW7, int1, p.5)

Participant 7 described this as a positive analogy, he had thought about his predicament and was comfortable to share his thoughts. That he "can observe" the other self is how he has kept himself positive throughout his experiences of illness. Charmaz writes of redefining self as accepting the past as that was then, but is not the self of the present and future (Charmaz, 1991, p. 227). This is the controlling self, sitting at the top of the well ready to pull up the self from the bottom of the well. Evolving illness is concerned with metaphor that explains and re-explains the self, according to circumstances.

A further example was the reflective metaphor offered by participant 13. In section 7.2.2.1 he compared his cardioversion to rebooting a computer:

They stop your heart for 10 seconds and reboot it. Sometimes your computer plays up, you turn it off for 12 seconds and it comes back, that's what they did to me. (CDW13, int1, p.1)

This metaphor was an explanation of how a cardioversion functions. It brings this tried and true clinical intervention in line with a modern icon, the computer. These visual or practical metaphors helped explain and remind the participant how biomedicine relates to him; this in turn became part of the participant's construction of illness.

Experiences of illness are influenced by how participants perceive themselves in social settings and how they learn from these social settings. In this study some participants had distorted perceptions about illness. The following section focuses on participants' perceived social constructions of health and illness.

### **7.2.3.1 Perceptions of social constructions**

This section has a lens on how the social environment helps construct notions of illness and health along with what is objectively known about health and illness. Perhaps more correctly, social constructions provide one layer of understanding about health, disease and illness. With this in mind, there follow excerpts that take into account particular perceptions of social constructions of illness.

Participant 2's mother has just died two weeks before admission to hospital. Added to this he had not prepared for a work training session which he was due to facilitate the day after his myocardial infarction:

I think the purpose of the heart attack was clearly brought on by stress. The day after I had the problem [myocardial infarction] I was due to run a training course on a new computer system which I'd done absolutely no preparation. I have got the thing installed, I haven't done anything else. No I don't recall any stress, I mentioned with my mother's death, like I got up and did the introduction at the funeral, I said it was an occasion of joy, she had got her wish and we were all happy to see that she was no longer suffering. (CPC2, int1, p.10)

The participant was reflective about what may have caused his cardiac event. He was talking through the possibility that stress caused his cardiac condition. He said in this first interview that he knows his smoking contributed to his ill health. There was no further discussion that his cardiac status had a variety of causative factors, for example earlier he explained he drinks alcohol in quantity (1½ litres of spirits per week), he smoked and he undertook little exercise (in fact took no exercise). The participant had not taken in to account how a number of his lifestyle

choices contributed to his heart condition, and that illness was perhaps greater than the sum of all parts.

Participant 2 was responding to a societal construction, that stress may very well have caused his myocardial infarction. He does not have prediabetes, none the less has comorbidity (gout, lung cancer now in remission, atrial fibrillation [medically treated] and a previous melanoma) and takes numerous regular medications. A social construction of illness provides more socially acceptable explanations for why an individual may fall ill. In this case, the social construction was about that which we cannot control, that pressure of work and bereavement may have caused stress which in turn may have caused an acute event of illness (myocardial infarction). This stress was likely to be subconscious, an inconspicuous detail. Alternately the participant may subconsciously have been aware of the stress and chose to ignore the detail.

In comparison the following excerpt is taken from an interview with participant 34 who had a more recent history of cardiac disease. He returned to hospital for a second admission for a second angioplasty. I met him immediately after the angioplasty, I was pressed for time so we met for our first interview a week after the angioplasty, in the outpatient department. When asked how he felt he replied:

I feel good, I feel particularly good, I feel just in a reasonably good state of health, I don't have any pain, I feel reasonably energetic. I really haven't noticed a great deal of difference before or afterwards, I know that some people do but really after my first stent I wouldn't have been able to distinguish before or afterwards at all but now that I've had the second one done I probably do feel a little bit more bounce in the step for want of a better word. I do feel a little bit better after this one but I couldn't say the difference has been huge. I am aware that some people you know struggle to walk across the road beforehand and then afterwards feel fantastic but I haven't really noticed a huge change. (CRS34, int1, p.1)

Societal constructions of illness are apparent in this excerpt. We live in a society of 'quick fix' and high expectation of medicalisation to be the fixer. Participant 34 was thoughtful about the result of his procedure and explained he did not notice much difference in his general health. He did however explain he felt 'particularly good' and energetic suggesting he valued these aspects of his well-being, that they were important to him, especially as we are constantly reminded by the media of the need to be and remain young, energetic and fit.

It is difficult to make any comparison between the participant in hospital and the participant discharged. The reflections are personal and each person has their own understanding of self as illness is evolving. Participant 34 was very conversant with his new diagnoses, so there was an expectation that his first interview would be reflective. Participant 18 too made statements which showed substantial reflection. There is a difference between the participant groups (those

interviewed later after discharge versus those interviewed in hospital) in terms of their understanding of their evolving illness, and is further examined in Chapter 9.

The following section highlights how participants tended to relive events that brought them to hospital, be they dramatic or otherwise less so. In reliving events participants highlighted how suddenly their lives were disorganised even chaotic. The following excerpts highlight how some participants weather the confusion and how understanding the confusion contributes to evolving illness.

### **7.2.3.2 Reliving a disarray of events**

A number of participants recounted the events leading up to their admission, and while they conversed they seemed to relive the events. They were animated, and seemed to be embattled again but made assertions that were reflective. The following interview segment is that of a participant explaining the disarray of events before his admission:

Participant: I probably left it a little later than I should have  
*Kim: Because you're sort of in a certain amount of disbelief potentially. . .*  
In a lot of pain . . . we stopped in the ambulance down by the wharf while they gave me some blood thinning drug I think it was, or shot number one of the blood thinning variety and then when they found out that I had had a brain tumour they decided not to put in number two, well when I got to hospital that was stopped, \$800 not \$1600 so I was told later. And then they fed me up on morphine down at [Emergency] then brought me up here [Cardiac Care] and then rushed me down to the cath room [cardiac catheterisation laboratory] then that was a success, told me they'd stuck a stent in and I woke up in a lot of pain, just about more pain than what the actual original heart attack was. (CSC8, int1, p.3)

Participant 8 explained that he delayed seeking assistance from the paramedics. This is an important point, because this is part of him making meaning from the incident. As the interviewer I stated how he may have been rejecting the notion of a further acute illness as he had only recently had neurosurgery. Participant 8 did not talk about “disbelief”, instead he explained experiencing “a lot of pain”, unprovoked in our conversation. The dialogue prompted reliving the pain, reflecting on how it affected him, and was retold on a number of occasions during this interview, even in the interview excerpt. The pain was a threat to self-control; he had already endured significant pain during the diagnosis and surgery of his brain tumour (discussed in interview 1). In the disarray of events the participant made an important link between both conditions: his brain tumour and the evolving myocardial infarction. He explains that he was not able to be fully thrombolysed because of his neurosurgical history. The combination of old and new diagnoses creates one layer of disarray. The participant returning to the issue of pain repeatedly highlights a further layer of reliving disarray, rethinking the chaos of that time.

Charmaz (1991) writes of living negative events, relived often, especially if reliving helps answer questions or the simple act of listening disperses stress. The issue of pain is addressed again in the next chapter, embedded in all three subthemes for the major theme, dialogue as caring.

Reliving inconspicuous detail involved consciously realising how signals of deteriorating health were evident but were ignored or simply did not register; this is indicated in Table 6.2 (Chapter 6) as blindness of the consciousness as expressed by Merleau-Ponty (1964/1968, p. 248).

Participant 8 explained how retrospectively he believed he had cardiac chest pain but did not follow it up as it accelerated:

In hindsight I probably have [had angina] thinking about it, I had one episode where I came to work one day walking up the wharf and it [chest] was a bit painful. It stopped, it was about a week prior [to admission], and so warning signs were there. Yeah, but you know never having any of these things before you don't really know what they are. But it went away and it was ok for the rest of the day. (CSC8, int1, p.4)

Recognising the blindness of the consciousness was a turning point in terms of learning and applying this learning in the context of understanding self in illness. Our dialogue revealed that the participant had chest pain only that particular day he described, nil further until he was admitted to hospital. As a new diagnosis, he had few signs and symptoms that cautioned him of his cardiac condition to prepare him for the disarray that was to unfold.

Reliving conspicuous detail involves reliving vivid incidents in one's life. Probably one of the most relived incidents relayed by participants were the various dramatic events that occurred just before their hospitalisation. Their stories were usually full of detail about near death experiences:

I mean I didn't know anything about the last one [cardiac arrest]. I just died and that was it, and then was brought back. So, I was out of it for some days before I really knew what was going on. I was in ICU<sup>5</sup>. (CGB22, int1, p.1)

There is a sense of relief in this excerpt, that one had lived to tell the tale and that even though mortality was close it had been beaten this time. There were many other conspicuous details that participants spoke of in their conversations of reliving disarray: making unplanned trips to the local medical centre (CAG21, int1, p.1; CDJ26, int1, p.5; CRY30, int1, p.1; CRL32, int1, p.5), calling and anxiously waiting for ambulances (CPC2, int1, p.3; CGB22, int1, p.2; CVP24, int1, p.3; CPK31, int1, p.2), relief when the ambulance arrived (CEH4, int1, p.3; CHS5, int1, p.4), being attended to urgently by emergency or ambulance staff (CSC8, int1, p.3; CRH9, int1, p.2; CFP10, int1, p.3; CFP12, int1, p.5; CMR17, int1, p.3; CDP20, int1, p.3; CRM27, int1, p.9;

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<sup>5</sup> Intensive Care Unit

CHC28, int1, p.2; CWA33, int1, p.3), taxi as ambulance (CKJ14, int1, p.7), losing consciousness (CRH9, int1, p.2; CAH25, int1, p.2), having multiple defibrillations (if conscious) coming to in hospital (CAH25, int1, p.2), or watching their own heart beat during an angiogram (CFP11, int1, p.5). A final relieved experience of disarray is that of pain, examined separately in section 7.2.3.4. All these examples were indicative of significant disarray, but managing to live through the chaos meant there was great benefit from this confusion in understanding illness as it evolved.

There was a sense that illness continued to evolve as part of being, as illness became more overt, more visible (Merleau-Ponty, 1964/1968) as conspicuous detail. Merleau-Ponty wrote: “the very pulp of the sensible [the visible], what is indefinable in it, is nothing else than the union in it of the “inside” with the “outside”, the contact in thickness of self with self” (1964/1968, p. 268). The “sensible” was the interpretation or meaning participants make of illness or being in the world with illness, the visible. As more conspicuous detail evolved the “pulp of the sensible” became more overt, the visible. As disequilibrium from the “inside” percolated up out to the “outside” the conspicuousness was more definable or visible (refer to Section 3.3.2), even if the visible was only definable as a disarray.

The following section scrutinises the body, how participants experienced the living body in the context of evolving illness. The body was always in some state conspicuousness in terms of signs and symptoms that participants described and interpreted. The living body was a significant point of deliberation and wonder for participants as they ventured to describe and interpret phenomena in terms of illness.

### **7.2.3.3 Experience of the living body**

The experiences participants often lingered upon were how the physical body failed and what could be done with it. The physical nature of the body characterised detail as detail became conspicuous. One participant expressed how he was relieved that eventually the source of his physical problem was identified, that what had been invisible was explicable and thus became visible:

Apart from the angina pain, which I now know is angina, my well-being is absolutely fine, until I get the pain. I could say that if it wasn't for that, I have energy, I'm happy – I was getting depressed, because I didn't know what this problem was. It wasn't diagnosed. That was the only real stress on me, but now, since Friday, even though I've had a heart attack, it's a great relief for me now . . . I'm happy.

Another thing I felt was that people think I'm malingering or something, I was getting this genuine pain, other people's perception wasn't that, because my daughter was just explaining to me, every time I had to stop [walking around Sydney] it wasn't even up a

hill, and I was apologising, but I just had to stop. They [the family] said “no, the look on your face – we knew you were really suffering”. So, their perception was that yes, I was suffering. (CDP20, int1, p.1)

In the interview excerpt participant 20 related pain, the lack of diagnosis and his experience of his body; he was happy once these three factors were linked and validated for him. The excerpt illustrates his genuine relief that his pain was indeed associated with a real diagnosis related to his physical body. What he knew was conspicuous to him because he understood his body, was also conspicuous to his family due to his observable suffering. Other participants expressed how they seemed uncertain that their experience of the living body was real, they could not isolate specific discernible anomaly. During this time of vacillation, participants scrutinised their bodies, or they hoped someone else would on their behalf, such as visiting the family doctor. Visiting the family doctor was delayed if detail were too inconspicuous to the participant, linking the experience of the living body to the notion of delaying seeking advice examined in Section 7.2.2.3.

The phrase ‘body experience’ belongs in the narrative concerning evolving illness because it concerns itself with personal experiences of the living body. ‘Body experience’ is found in the academic literature (Charmaz, 1995; Kvigne & Kirkevold, 2003; Merleau-Ponty, 1945/1981), and in the following excerpt:

I look at it on the bright side I suppose by saying I haven’t lost of any of my strength physically. . . I don’t see that I can’t continue to do most of the things I already do at this stage provided I listen to what other people advise me. If I want to pour concrete under the deck I can do so, it means that if I want to go duck shooting I can but I have got to say I am not going to go out for three days, I am only going to go for 1½ . . . well you know as an example. . . I think your body lets you know pretty quickly if you can’t do something anyhow. (CRM27, int1, p.1)

This excerpt is about the experience of the living body in illness. It reflects how the participant was orientated toward his body and personalised the ‘body experience’. The body “lets you know”, directed the participant, alerted the participant of his limitations. The ‘body experience’ of illness is concerned with this type of commentary, where the participant began to describe their experience of illness by expressing what their body did, and to some degree an interpretation was evident by expressing what the description meant. The following interview excerpt comes closer to revealing the ‘body experience’, the dialogue showed a differentiation between what the body did (description) juxtaposed to what their body was (interpretation):

I had had four days of chest pressure, on and off, which I thought I managed quite successfully with breathing, regulating my breathing, relaxing . . . (CVP24, int1, p.2) [Then the pressure returned] and the pressure resolved before the ambulance got here . . . and I still felt quite funny, felt a bit of a fraud, but also knew that something had happened that needed addressing . . . and so the ambulance people then put me on the

ECG and then that showed a blip and they said, “Oh, well, we’ll treat this differently now, we’ll treat it as heart and give you an aspirin” (CVP24, int1, p.3)

Participant 24 commenced the above interview excerpt with a bodily experience of chest pressure which she dealt with through meditation i.e. she was able to override the physical, implying that she was able to control the physical by using her mind to impose an equilibrium. As the pressure returned the physical became more prominent and superseded all. It is interesting to note the comment made by ambulance staff as highly orientated to description i.e. what the body did. The comment made by the participant that quotes the ambulance staff showed how quickly health professionals focused their attention to bodily experience as evolving physical illness rather than an experience of evolving complex illness.

The experience of the body as “‘the living body and life’ . . . vividly presents the absolute inseparability of the living body and life itself” (Gadamer, 1993/1996, p. 71). The participants predominantly talked about their body as a physical entity, as an objectification (Merleau-Ponty, 1945/1981). Participant 10 made the connection between the body and this being inseparable to life:

I don’t care about dying. That doesn’t worry me. But I do want to be able to live. There’s no point in being on this earth if you can’t live. (CDM10, int1, p.7)

Other participants spoke of the experience of the living body in a more social context.

Participants explained how the body has a social role, to appear indestructible, a symbol of health exhibited by how many sick days have been taken from work:

I always keep very good health, I do not get sick, I do not get unwell. Maybe that is just a male thing. The amount of leave I have had in thirty seven years work is probably in total about ten days. I don’t get sick. If I get sick I get very sick. (CRG15, int1, p.1)

This excerpt illustrates how the living body became entwined in social roles such as becoming “very sick” rather than “sick”. Is it better to be “very sick”? There was also a hint of social control in this excerpt wherein it seemed better to have endured the living but sick body, rather than have taken sick leave from work to rest the living body.

Excerpts in this section were included in these findings to express how people talked about the living body. To continue this theme of experience of the living body, the next section concentrates on the body experience of pain as described and understood by participants.

#### 7.2.3.4 Awareness of pain and the living body

The experience of pain was keystone throughout this research. It was a recurring topic the participants described and (re)constructed in both interviews 1 and 2. All participants described some degree of cardiac pain or alluded to the lack of its presence. Pain became a way of living, the experience of pain was consuming of their energy, even an expectation. The experience of pain was such that evolving illness was distorted by the pain of the living body. This was further complicated by the bewildering array of manifestations of cardiac pain that may be confused with other sources of chest pain. Participant 33 described his experience of cardiac pain:

I supported my head with my hands, I felt a bit hot and I had work to finish and so I thought I am alright now so I got up and went to the photocopier and all of a sudden I had this pain tightness in my chest, all down my arm, up in to my jaw and up the left side of my neck; it was already tight and uncomfortable. Then I started to hyperventilate, started sweating profusely and the pain was quite a pressure on the chest, it wasn't like a sharp stabbing pain . . . it was a pressure like a weight, your chest was being crushed. (CWA33, int1, p.2-3)

This participant's experience of pain was different to what he may have read about or discussed with other people who experienced cardiac pain. The body experience of pain is the experience of or in the body: for participant 33 it was pressure, while another participant experienced "tightness in my chest"(CAH25, int1, p.2), and yet another "had terrible pains up here [chest] that was new" (CDJ26, int1, p.4), while participant 28 "had some tightness and some back pain . . . the tightness was like an elastic band kind of around my ribs" (CHC28, int1, p.1) as samples of pain experienced of the living body. These experiences of pain collectively dominated a large portion of the dialogue throughout interview 1. The principal point of focus was that pain was the experience of the participant as described by the participant, it was their awareness of pain. "I am the person who is this body" (van Manen, 1998, p. 16), hence the awareness of pain may be a new awareness. It was as an awareness of their body that participants chose to describe pain as a conspicuous detail. Interpretation of this experiential description was yet another layer of constructing the experience of the living body as it pertained to illness.

When pain was not expected, or pain was unexplained, participants voiced their confusion.

Participant 8 had not anticipated pain during his treatment:

[They] told me they'd stuck a stent in and [I] woke up in a lot of pain, just about more pain than what the actual original heart attack was. When the blood started rushing around again it was actually just about worse. They acknowledged there was going to be pain, I just didn't realise it was going to be as bad if not worse. (CSC8, int1, p. 3-4)

The participant expressed how he had pain while a stent was placed in the partially occluded coronary artery. Other participants in this study also described the same experience. Although significant pain was experienced, usually the effect of re-establishing blood flow through the

near-occluded artery, followed by a gradual subsidence of pain, were events that outweighed the negative experience of pain.

Other participants trivialised their pain, were stoic and did not wish to acknowledge the presence or absence of pain. One participant made no great effort to describe pain until his second interview, even then he briefly discussed his pain as inconsequential:

No [I do not have pain] not really . . . Well little murmurs now and then but I don't worry about them. I just get a little pain here [indicating his chest] but I don't worry about it. I try not to think it's my heart I try to pass it off. (CKS19, int2, p.4-5)

Participant 19 may have been in pain, but directed it to the invisible, that which is pre-reflective (Merleau-Ponty, 1964/1968). To complement this, Gadamer explains pain as symptomatic of disequilibrium in the living body, a subjective sensation representative of physical imbalance (Gadamer, 1993/1996, p. 108). It is by attending to pain that evolving illness may be curtailed or temporarily redirected. Gadamer explains further, it is the role of health professionals to care for health in the broadest sense, hence caring for the body with physical pain, but also coming to understand that patients have various awareness of pain of their living body.

Illness with pain evoked a turning point for the participants of this study. In order to control pain people adapted to new medications, undertook new procedures or returned to old ways of coping as needs dictated. Consequently people remade their life, reconstructing their understanding of illness, pain as a conspicuous detail, a detail of the complexity of illness.

### **7.2.3.5 Illness evolves by remaking life**

From the previous sections illness is a dynamic process, ever evolving. To adapt to this evolution, participants reflect on and express how they have adapted, even while in hospital. This process of adaption is noted in those participants already in a short time remaking their life. Charmaz wrote: "the problems with which ill people struggle are existential; their solutions are often organizational" (1991, p. 138). To help explain this point I turn to participant 6 (a 79 year old woman at the time of interview) with wide spread coronary artery disease:

. . . the angiogram. I've seen the picture of my heart and he's shown me the wriggly bits that cause the angina and . . . it wasn't suitable for a stent. . . but he [cardiologist] did say that the only thing they could really do for me was a by-pass and he said you're not robust enough. Isn't that kind? And besides at my age I wouldn't want to go through that . . . I've just run out of steam. I can't garden like I used to or walk like I used to . . . I honestly don't think there's anything much more they can do for me. Except give me medication and keep me ticking over. (CIM6, int1, p.3-4)

Participant 6 grappled with an evolving new construction of understanding complex illness. The existential<sup>6</sup> identification that there is no cure is real for her. She is philosophical that her only option is to “keep me ticking over”, and she is resigned to an ongoing experience of the living body, waiting for her body to deteriorate, acknowledging that this will happen. Participant 6 had had numerous admissions to control her chest pain, so she had had some time to reflect upon what her continued sporadic chest pain means, and how the existence of chest pain colours her life. Remaking her life is about her ‘ticking over’ and coming to terms with what this means.

A further excerpt comes from an interview with participant 13 who is remaking his life:

They [doctors] put me on new medication and doubled the odd tablet. This Omeprazole or Losec [the surgeon] put me on that because I was getting reflux, I’ve been on it for quite a while, quite a few years. This is the spray in tablet form, Corangin, they’ve doubled that, it’s up to 80 mg [a big dose]. That one [Felodipine] there is a new one, been on that about nine months now. [Cardiologist] put me on that . . . I did ask them if there was any chance of cutting down on tablets and they said only if I wanted to die . . . this one here [Betaloc] I said well look shall I stop it? But that’s gone up to 190 mg a day. They [doctors] told me I would be on that for life and if I ever stopped it I would drop dead. So I’ve kept it going. (CDW13, int1, p.7-8)

From this narrative the participant understood that if he discontinued some of his medications he was likely to die. Participant 13 shifted through various phases of remaking his life according to the medicalisation of his life. Both participant 6 and 13 have significant coronary vessel disease so cannot undergo angioplasty and are a high risk for CABG surgery. Consequently they are both resigned to remaking a life with polypharmacy to sustain them. Remaking a life has meant that as illness evolved, organisational solutions became less effective or absent. As organisational options diminished, existential contemplation about living with illness proliferated.

### **7.3 Conclusion**

In this chapter participants shared their descriptions and a variety of interpretations concerning how they looked inward. In looking inward participants found elements of the invisible disequilibrium. Participants developed a consciousness of the detail of their lives that were conspicuous or becoming conspicuous as individuals living with complex illness.

This chapter explored the first major theme of the thematic framework which is invisible disequilibrium supported by three subthemes: losing equilibrium, becoming embattled and

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<sup>6</sup> Existential: the affirmation or implying the existence of something, philosophically relates to the individual existing as free and responsible agents determining their own growth (Gadow, 1980; Meiers & Brauer, 2008).

evolving illness. The subtheme becoming embattled is supported by embedded subthemes: humour alleviating embattlement, contemplating surgery, and delaying seeking advice. The subtheme evolving illness is supported by embedded subthemes: skewed perceptions of social constructions, reliving a disarray of events, experience of the living body, awareness of pain and the living body and illness evolves by remaking life. Numerous interview excerpts described how participants were constantly working with inconspicuous or more conspicuous detail to live with illness.

The following chapter is a third findings chapter which aims to move further into the thematic framework by describing and exploring the major theme, dialogue as caring. This exploration is supported by interview excerpts that illustrates the subthemes as a restorative dialogue which is caring and is instrumental in constructing an understanding about illness. To enhance clarity, researcher interpretation is included in the presentation of this portion of the thematic framework.

## Chapter 8

### Interpretive findings: Dialogue as caring

#### 8.1 Introduction

The participants explored their experiences of a dialogue of caring by reflecting upon, describing and interpreting the inconspicuous and conspicuous detail of their illness, as people with CVD and prediabetes or diabetes. Theoretical underpinning to this research further guides understanding of the epistemological constructions of complex illness as it surfaces. Gadamer's philosophical work as related to health, illness and well-being and Merleau-Ponty's philosophical perspective are both drawn upon to further explore and interpret the participants' experiences in keeping with the interpretive paradigm. The findings in this chapter reinforce aspects of the participants' whole story as expressed in Chapter 6.

Chapter 8 is concerned with the dialogue as caring (Section 8.2), a focus upon participants' interpretation of their experiences as complex illness developed. For this reason, both interviews one and two provide excerpts to exemplify the subthemes of dialogue as caring. The subthemes to dialogue as caring are: restorative dialogue (Section 8.2.1), caring (Section 8.2.2) and (re)constructing illness (Section 8.2.3).

The subthemes for this major theme reveal a number of clustered notions which were common across interviews. Just as for Chapter 7, these clustered notions were embedded hence the continued use of the term embedded subtheme, further relating to in/conspicuous detail. The embedded subthemes enrich comprehension of 'the whole', consequently these themes are a natural progression to help refine the essence of the subthemes of the dialogue as caring.

Restorative dialogue reveals embedded subthemes: dialogue for sharing burden (Section 8.2.1.1) and medicalisation of detail (Section 8.2.1.2). Caring further depicts embedded subthemes as life routines (Section 8.2.2.1), conspicuous medications (Section 8.2.2.2), conspicuous risk (Section 8.2.2.3) and caring for self (Section 8.2.2.4). (Re)constructing illness also has embedded subthemes as new constructions of illness (Section 8.2.3.1), recognising well-being in constructions of illness (Section 8.2.3.2) and constructing complex illness (Section 8.2.3.3). All these themes embody the detail of illness becoming increasingly

conspicuous. These conceptualisations afford a starting point from which to construct knowledge germane to clinical nursing.

## 8.2 Dialogue as caring

A dialogue of caring is orientated to detail that is or is becoming conspicuous. This is indicative of participants having had time to reflect and consider their lives and how illness relates to 'the whole'. 'The whole' conceptually is important to the caring dialogue. Gadamer wrote ". . . we must understand the whole in terms of the detail and the detail in terms of the whole" (1960/1998, p. 291) and relates contextually to Section 3.3.4. Here understanding 'the whole' becomes key to day-to-day consciousness.

In this study participants were initially embattled, living in the moment, determined by a focus on the minute-by-minute world. When participants were interviewed for a second time they were prudent and solicitous in the use of their language to re-explain real events such as near death or a time of severe pain. Their language was more measured as they made meaning of their experiences.

In both interviews the session began with asking the participant to state why they answered the question "in general how would you say your health is?" as excellent, very good, good, fair or poor. Participant 21 was asked why he answered the question as fair:

I put fair because of what has happened in the last week [had a myocardial infarction]. Had I been asked this a week ago I would have probably said very good. Now, I understand the picture internally in my body which I didn't before, and purely that answer is based on I guess, one part of my body, and that's my heart, and also having had the angioplasty yesterday. That painted a very real picture of the condition of my arteries. So, that's exactly why I've put fair. (CAG21, int1, p.1)

The participant was answering the first question of the interview with a description. He stated "I understand . . ." but this was tempered with a description of his experience of the living body. It gave some indication that he had taken time to reflect upon his experience of the angioplasty, to consider what it all could mean. His attention was on what is real to him, his physical self. These aspects constitute the visible or conspicuous whole at this time.

Ten months later participant 21 was interviewed again. The participant reflected upon answering the same question in interview 2 as in interview 1, "in general how would you say your health is?" This time the participant has answered very good:

I think in hindsight it's better to know what you didn't know a year ago, I think internally there was stuff going on which I may not have felt physically but obviously

especially with the condition of my arteries which, it's not good to not know. So I feel it's better to know what I'm dealing with now. I actually feel quite well other than I think the medication making me feel very tired. . . every week at night you just have to go to bed earlier, you just crash, pretty much hit the wall, I think that's how I describe it . . . can be quite early sometimes which I never used to have to deal with. But your body almost shuts down, you think well you've got to go to bed and that's it. . . . I wouldn't say there's a pattern but it's quite regular, certainly it's not once a month it's more regular than that, it's at least once a fortnight, you don't have that energy late in the evening you used to have. But I've been told it's the Betaloc<sup>7</sup>. . . I've actually been told to break the tablet in half cause I was taking a full one in the morning, so I do a half at night, half in the morning. (CAG21, int2, p.1)

The participant has reflected (“in hindsight”, “I think . . .”) and considered the extent of the information he did not know about, and the double negative (“it's not good to not know”) indicating he was in no doubt that he needed to know what the physical status was of his heart and coronary arteries. He had a greater focus on his disease (“better to know what I'm dealing with now”), and was aware of his medication causing a pattern of tiredness, even though he contradicts this saying “I wouldn't say there's a pattern but it's quite regular”. He sought advice on his perpetual tiredness which required a change in administering the beta-blocking agent. Although this excerpt is strictly speaking not demonstrative of much abstraction, there is perceptible understanding of his changing body which he endeavoured to accommodate in a new construction of illness. As an example the participant explained “. . . pretty much hit the wall, I think that's how I **describe** it, I hit the wall and can be quite early sometimes which I **never used to have to deal with**” (CAG21, int2, p.1) where he described and then made an effort to understand (second bold section of sentence).

In the second interview participant 21 was very medically focussed, as an example, the discussion dwelled on medications. This is a pervading pattern throughout this findings chapter, the perpetual medicalisation of people with illness. Participant 21 had adapted to a medicalised routine of medications and side effects, physical health dominated. The participant knew the researcher is also a nurse. Is the participant subconsciously in dialogue with the nurse or the researcher? Is the dialogue heavily laden with medical terminology because the participant wished to discuss his medicalised body or his experience of the living body? Is the medicalised body still the dominant feature of people living with illness? These questions surface as the tone of this interview and many other interviews, examined aspects of their medicalised life.

Participant 21 portrayed one particular interpretation of the major theme ‘dialogue as caring’. There are many more examples to follow that represent the participant interpreting more about

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<sup>7</sup> Betaloc = Metoprolol is a common  $\beta$ -blocker, tiredness being a common side-effect

their condition. The following is the first of the subthemes that brings together what participants talked about indicating a ‘restorative dialogue’.

### **8.2.1 Restorative dialogue**

A restorative dialogue comprises the conversations or exchanges that participants had with family, significant others, friends, and health professionals. All those that participants came in contact with contributed to a dialogue that began to reveal the inconspicuous detail and align this with the nature of illness. In this context, to reveal also meant to become motivated, so the restorative dialogue tended to give the participant insight in to their experiences and so they potentially became motivated or found new meaning in their lives with illness. Some participants came to realise that “something is lacking [and] is connected with the idea of balance” (Gadamer, 1993/1996, p. 55). Immediately after their acute episode of ill health, bringing them to hospital, some participants were significantly motivated by these events and experience to improve their health and enhance their quality of life. Motivation came in many guises, and for some, did not come at all. Gadamer described this phenomenon as an “idea of a restoration of equilibrium” (Gadamer, 1993/1996, p. 55). The restoration incorporated some level of dialogue with significant others and health professionals on the pretext that it would be beneficial.

Communicating with others is essential to accessing health care. Therefore the participants’ restorative dialogue was closely linked to caring as a process leading to corresponding health outcomes. Hence the findings in this section are often awkward to differentiate clearly as restorative dialogue and caring, they are a nexus of health care options. For this reason excerpts that follow in this chapter representing both subthemes are indicated.

The dialogue highlighted what participants expressed as precarious aspects of their everyday life because these activities accelerated cardiovascular disease and prediabetes. For example, participants talked about drinking alcohol, taking added salt or butter in their diet, living a mainly sedentary life and smoking. Stating what they had done is dialogue, and expressing some attentiveness, self-awareness or motivation to alter these habits that carry some aspect of risk, is the restorative dialogue. This dialogue is about what is acceptable to change from the participant’s perspective. Participants talked about what they as a patient knew they needed (Jonsdottir, et al., 2004), rather than what the nurse (or other non-health professional or health professional) believed the participant-as-patient needed.

We return to the question, “in general how would you say your health is?” Participants could answer excellent, very good, good, fair or poor. In interview 1 participant 19 was asked why he answered the question with very good:

*Kim: so why do you think your health's very good?*

Participant: Well, I thought I was good before my heart attack. I felt I was right as reign. I was loading trucks and that. (CKS19, int1, p.1)

This was the extent of our conversation about the question. It was short, descriptive but actually spoke volumes. It was as if the period of hospitalisation did not exist. After the interview it was discovered that the participant's wife had died about five years ago and he glossed over the fact that her death had been unnecessary, a mistaken diagnosis. He did not wish to make a fuss over this misadventure, but it had rattled his confidence in medicine, he made it clear during interview 1 that he was not cooperative in taking medications:

*Kim: What medications are you normally on?*

Participant: None . . . I don't take medications . . . Guess they'll go in the bin, is that all [my] medications? [looking at a list]. . . I thought that – the amount of pills they've given me. I said shake me – I'll rattle. . . No, I'll take them, because – I'm a bugger for taking pills though. (CKS19, int1, p.3-4)

This excerpt may exemplify a blasé attitude, but did represent his life with illness, a minimal dialogue as caring concerning medications. The interpretation taken from this was that he preferred to not take medications (“I don't take medications”) and then changed his mind, wished to keep the dialogue open with health professionals (“No, I'll take them . . .”), and explained that he was not reliable (“I'm a bugger for taking pills”). He was candid with his self-analysis which was taken to be indicative of self-awareness and a willingness to cooperate as he has insight into his evolving illness, overshadowed by the circumstances of his wife's death. At the end of the excerpt, his reflection on his ability to take medications is edifying, the word “though” at the end emphasising the potential development of a restorative dialogue.

The same participant (19) was reinterviewed about ten months later. Returning to the question, “in general how would you say your health is?” he told me:

I feel I'm good. I don't feel down in the dumps, I don't feel anything, I just feel like I'm really good. I never get depressed it takes a lot for me to get to that. I've had no problems [with my health], I had a bit of a cold that's about all. (CKS19, int2, p.1)

Key dialogue here was “I don't feel anything”, not that he was depressed, more that he wanted to keep the dialogue brief, work with health professionals on his terms. He talked about his work and his family and found that he was very much dedicated to both, he was animated and involved. His dialogue of caring was with his family, with people he could trust, not with

interviewers or health professionals, the dialogue of caring included detail that remained firmly inconspicuous.

### **8.2.1.1 Dialogue for sharing burden**

The restorative dialogue was a time for sharing a burden. The dialogue became a conduit for sharing information about illness, how it is developing, how it may potentially be managed. All the participants had to manage an amalgam of diagnoses contributory to illness. All participants had CVD, some had a high blood glucose that persisted, others had a new diagnosis of type 2 diabetes, and further participants had to have CABG surgery, a few participants had their CVD managed without interventions, while other participants had further new diagnoses after their first interview.

The participants who had further new unanticipated diagnoses after their myocardial infarction did not number many but during the second interview they did dwell on the new diagnosis. When we met for the second interview they wanted to tell their story and were eager for a dialogue about their further conspicuous detail. They had questions they wanted answered. As a researcher with a clinical background it was inescapable that I was interested in their recent clinical development. Our dialogue became a forum to share their burden about their experience of living with illness with new developments.

One participant found he had yet another significant diagnosis to contend with after his myocardial infarction (at interview 1):

*Kim: Well you look better than last year, you looked really tired*

Participant: Well that's probably the [sleep] apnoea. I think it was getting worse I was getting drowsy quite a bit, I could sleep anywhere which actually had some benefits, but I was also driving a lot more and I was driving up to [central New Zealand] and there were a couple of occasions there where I almost fell asleep at the wheel so that was scary. [I'm] a reluctant person to go to a doctor, you know men what they say about us at best I was always a bit reluctant but I thought I've got to get all these things resolved . . . I heard that a friend of mine also was going through the same thing so we started talking about it . . . and I said to my doctor, I think it's starting to impact [upon] my day to day quality of life so that's when we did a questionnaire and because of the heart she said you should really get on top of that so we started talking about it. (CRS34, int2, p.7-8)

The participant recognised that he had allowed his health to deteriorate before he became motivated to make a determined effort to regain his health. Inconspicuous detail became very conspicuous when he nearly fell asleep at the wheel as a result of his sleep apnoea. There was a turning point (nearly sleeping at the wheel) that drove the participant back to the doctor to push

for what he identified were his needs “I’ve got to get all these things resolved”, and “it’s starting to impact [upon] my day to day quality of life”. The conversation developed further in the interview about diagnosis and management of his sleep apnoea. For example we discussed what his progress was using a continuous positive airway pressure (CPAP) machine at home, each night, what are its merits and how did it interfere with sleep. He has a friend with the same problem so they compared notes:

I might see if I can trial the nasal one [CPAP machine] because my mate’s got that one and said it’s a piece of cake I just find the rubber sort of chafes on your cheeks at night it’s not the most comfortable thing. It worked for one night and it’s eureka you know but it’s, a lot of these things become sort of obvious on reflecting [upon] the change. (CRS34, int2, p.9)

Participant 34 was happy with the outcomes of using the CPAP machine and was already looking at ways of refining the use of the machine i.e. moving from a full face mask to a smaller nasal mask. He remarked that in hindsight the change has been “obvious” but often we cannot see that which is inconspicuous, the invisible. Our dialogue dwelled on the participant’s identified therapeutic needs. He had been to his doctor, impugned his health at that time, and acted upon his needs as person living with complex illness.

Participant 30 also revealed a dialogue that appeared to share a burden. The participant had CABG surgery and then after surgery his repeated blood tests consistently indicated he had type 2 diabetes. During the second interview we had a conversation about his new diagnosis. I asked him directly whether he had diabetes:

I don’t know. When I had my blood tests or liver enzyme test or whatever test they do, said it [blood glucose] was high. Just after the surgery my General Practitioner said it was traditional that it is fairly high and so we did a few blood tests and he prescribed tablets for diabetes . . . metformin<sup>8</sup> . . . my General Practitioner gave me a scale, “If you’ve got anything 4.0 to 11, anything below 4.0 is good, anything above 4.0 . . . you’re getting to the point where you may be suffering from diabetes,” and I was like 4.5 or 4.8, they said, “But then you’ve just had an operation, that may have been playing with your enzymes as well.” So he [the general practitioner] said that and it did drop a little bit, then he said, “Well, just to be on the safe side we’ll prescribe you some tablets as well, metformin,” and since he’s taken bloods [after] that it’s [blood glucose] very low. (CRY30, int2, p.15)

The conversation was orientated to the mechanics of his new medical diagnosis, a reconstruction of illness with a substantial medical focus. The dialogue briefly highlighted his disappointment in having diabetes (“I don’t know”) in a veiled attempt at not really being surprised. He seemed to take on board the doctors “scale” and had successfully reduced his fasting blood glucose. Reading further into the interview transcript (page 32) the participant

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<sup>8</sup> Metformin is an oral hypoglycaemic agent commonly given to people who have new diabetes or prediabetes in New Zealand.

mentioned a few times that his sustained high blood glucose level may be elevated because of the large surgical procedure he had. The participant is hopeful that his blood glucose regulation will return to normal status. However he realised that genetically he was likely to continue to wear the mantle of diabetes:

When we [members of his family] get older it [fasting blood glucose] does creep up. Even mum said she's been watching her diet, but as time progressed her diabetes numbers [HbA1c] were increasing . . . she's taking the same tablets [as the participant]. (CRY30, int2, p.34)

The dialogue was that of sharing bad news; conspicuous detail that was hoped to avoid became unavoidable. The dialogue in the above interview excerpts revolve around a great deal of medical information. The notion of medicalisation was highly prominent in all the interviews. Some of the descriptions and interpretations that participants offered were balanced with information about themselves as people living with illness, but many participants were steeped in the culture of being a patient on medications with appointments to keep and goals to achieve. The following section looks at what participants said about their medicalised details.

### **8.2.1.2 Medicalisation of detail**

Dialogue helped surface the extent of both conspicuous and inconspicuous detail pertaining to illness. Throughout both interviews but more so in the second interview, participants used medical language to identify what it was that they were experiencing in the past, currently and even prospectively. The following section describes and to some degree interprets the embedded subtheme medicalisation of detail.

Medicalisation refers to those aspects of everyday life that are dominated by the science and political drive of medicine. The medicalisation of participants' lives in this study is the singular most ubiquitous observation in every sense. Participants seemed to divert the interview conversations back to some aspect of medicalisation, as swiftly as attempts were made to divert it away by myself as interviewer. For example I spoke with a participant (interview 2) who had experienced chest pain between interviews. I asked how intense the pain had been:

Participant: Pain wise was probably around about a 6, 6.5

*Kim: Out of 10?*

Participant: Yes. (CNB23, int2, p.7)

The participant answered in the clinically well known language used for pain assessment, maximum pain being 10/10 and no pain 0/10. His answer used medicalised language. A further example is included here from the second interview with participant 28. We were discussing HbA1c levels:

Participant: So the normal is 8?

*Kim: Well it's not a normal, there's a range they like to talk about*

Which is what?

*Between 2 and 7.8% and yours is 8.2% it doesn't mean that you immediately have diabetes but it does mean*

That's what they call prediabetes is it?

*Well it's in the grey area. . . (CHC28, int2, p.7)*

This excerpt again shows how confident some participants became in grasping technical information which was quickly assimilated into their language. There is almost a sense of acculturation, adopting what seems to be considered a more universal language and yet homogenates difference ("the normal is 8"). When as the interviewer, I tried to avoid homogenised descriptions suggesting a range, the participant immediately interrupted with a diagnosis (prediabetes), perhaps seeking confirmation of her own classification. Medicalisation of detail is extensive, and was accepted or at least tolerated by many participants. A further point of interest was the difficulty with which the role of interviewer was maintained. Frequently I found that participants had an expectation that I would answer clinical questions (medical questions), hence the inevitability of conversation slippage demanding that my researcher focus detour to a nurse clinician's focus. It was not uncommon to indicate to participants that they were better to direct their clinical questions concerning their care to the clinical staff on the unit.

The language of medicine was peppered throughout the interviews. Six participants were confident about what high blood glucose indicated. Each time participants were asked the question "what does it mean to have high blood glucose?" the participants would counter with further questions, asking what diabetes was or "are you thinking that I am showing some symptom of diabetes?" (CRW7, int1, p.12). All participants had heard of diabetes but some were certain they did not have diabetes, "I'm too healthy to have diabetes" (CKS19, int2, p.10). When time was taken to talk with participants, everyone understood what diabetes was; this was important in terms of entry into the study at the time of recruitment, as we were recruiting people who did not have a diagnosis of diabetes at entry to the study.

Further evidence of medicalisation was noted by a perceptive remark made by participant 22 about the language used in restorative dialogue:

. . . what I found is in hospital you don't really take it all in what's being said to you, and a lot of it is quite technical . . . when I got hold of my file the way everything is recorded is very technical and even the discharge report that you're given when you leave hospital is highly technical and mostly meaningless to the ordinary person. (CGB22, int2, p.1)

Participant 22 had a myocardial infarction which had occurred prior to interview 1, the second time he was interviewed after CABG surgery. The surgery itself was without incident but post-operative care was marred by an adverse event which he wrote about to the District Health Board to ensure future public safety. After the event of his myocardial infarction, details were more conspicuous, however, the language of medicine rendered detail less conspicuous as the language rendered detail inaccessible to “the ordinary person”.

The adverse event participant 22 experienced was related to receiving an incorrect intravenous medication. He recounted that the staff in the ward (high dependency unit) where he was at the time, had followed up with some action after the adverse event, but he personally was unaware of this:

When I read the file [after asking to come back to the hospital after discharge and read his file] . . . apparently the ICU people had followed through but no-one had ever spoken to me, none of them had ever spoken to me. So I had a couple of issues - I thought I deserved an apology which I hadn't received and an explanation, and I wanted to know what they were doing about it so that it didn't happen again to someone else. [He did receive an apology] The Director of the ICU was excellent once he found out what hadn't been done and I had a very useful meeting with him and the head ICU nurse about a couple of months' later, which my daughter came with me to, and they explained what they were doing in terms of systems etc, I came away satisfied with that. (CGB22, int2, p.2)

The participant needed assurances that the health professionals responsible for the incident had been reprimanded and lessons learnt from his experience. The restorative dialogue was with the Director of the unit who kept the participant informed about processes in place to avoid mistakes in future. The remaining issue for him was that his adverse event was trivialised and became an invisible aspect of medicalisation, another inconspicuous detail in the eyes of health professionals:

So if you [as a patient] come through it [adverse event] unscathed I'm not sure that the learning goes beyond the particular hospital which is something I'm still pondering. In other words, Health Safety and Quality Commission<sup>9</sup> or whatever it's called publishes a report each year which is disseminated across all the district health boards with a view to saying these are the sort of issues that need to be looked at, but my sort of issue, because it was a statistic which featured at the third level of risk management because there was no consequence doesn't make it into their report. I mean, I nearly died in the [unit] basically because of this event. [Therefore it is] only in an emotional consequence I think. There was no physical [consequence] I suffered no ACC<sup>10</sup> injury, that's how it's determined. [The unit] had “investigated” in quotes, without talking to me and concluded that it was just a simple error. (CGB22, int2, p.2-3)

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<sup>9</sup> The Health Quality & Safety Commission was established under the New Zealand Public Health & Disability Amendment Act 2010 to guarantee all New Zealanders have the best care (health and disability) using available resources (Health Quality & Safety Commission, 2013).

<sup>10</sup> ACC = Accident Compensation Corporation

Participant 22's excerpt demonstrates perspicacity in dealing with the highly medicalised environment that he had to negotiate to assure an outcome from his adverse event. As further medicalised conspicuous detail (errors in this case) occur in such an environment, it is likely the consideration of health professionals involved will have their attention taken away from this particular incident and focussed on the next "simple error". As an example of medicalisation as detail, the above excerpt is an extreme illustration of how medicalization undermines a therapeutic restorative dialogue.

Participant 22's experience and interpretation of the adverse event involved a restorative dialogue that is likely to have included his family and significant others to make meaning of this incident. Participant 22 was highly motivated to act upon this event as he recuperated from his CABG surgery, particularly as he came to realise the extent of the imbalance of his experience. As a final remark, the "restoration of equilibrium" (Gadamer, 1993/1996, p. 55) as a restorative dialogue was achieved after much energy was spent deliberating over how to achieve goals set by the participant in a restorative dialogue. The following subtheme dwells on this very matter; how participants planned to achieve the various targets they set themselves and how they planned caring for themselves. Alternately, did participants in the main care for themselves or were others designated to care for participant?

### **8.2.2 Caring**

The subtheme caring is indicative of the activities that participants undertook to set in motion a restorative dialogue. In Section 6.5.2, the summary description of caring in Chapter 6 explained how the restorative dialogue represented what participants had learned and what potentially motivated them, while caring represented taking responsibility to achieve goals to resolve disequilibrium. Caring denotes what the participants actually did.

Up to this point the findings have reported participant descriptions and interpretations of complex illness. It is at this juncture attention is turned to what participants actually did during their time of recovery as this too is a vital aspect of living with illness. There are many issues reported here about lifestyles, referred to as life routines in this document. The reporting includes: life routine changes that worked, attempts made at changing life routines and for others the lack of success in changing life routine.

Participant 9 had a significant family history of cardiovascular disease. The participant explained he had various life routines that were not conducive to healthy living:

It's just that I have bad eating, my diet was pretty bad. Takeaways, fizzy. . . pretty much on a daily basis. . . McDonalds, KFC. I drive around a lot for work and around lunchtime if I pass some takeaways which was pretty common I'd just drive-thru. So [for his work] half the time I'm at my desk and half the time I'm driving around. Initially when I started working [there was some stress] but I've learnt to cope with it. (CRH9, int2, p.2-3)

He explained further:

Participant: I think that I've dropped off a lot on my exercise, well I know I have and I haven't been to the gym in ages, haven't been for a walk in a long time.

*Kim: Because?*

Lazy [due to] stuff, life, weather. . . Yep I like to do that [blob out]. . . [watch] TV. . . a lot of sports and comedy. (CRH9, int2, p.4-5)

The participant's tone and demeanour are pessimistic in this last excerpt, however he did explain that his diet had improved:

The last four months probably I haven't improved, just gone back to very little exercise. . . well no I eat pretty good while I'm at work, you know I always go and get fruit so I eat fruit during the day and a sandwich maybe and then at night do this takeaway stuff about four times a week. Then on the weekends it's usually not great the meals we have. (CRH9, int2, p.6)

Participant 9, like other participants, had set goals, some perhaps difficult to achieve, often because they did not fit in with family (or other) routines, daily life did not accommodate their new needs. Even though this participant had let exercise languish, his diet had improved. He may have thought he has achieved little but he had been able to alter his diet for lunch. The culture of eating is a conspicuous detail throughout the interview data and is looked at in more depth in the following section, eating as part of life's routines.

### **8.2.2.1 Life routines**

Life routines is an embedded subtheme highlighting activities participants engaged in to improve their health and/or avoid further illness exacerbation. Participants concentrated on two particular life routines, diet and eating habits coupled with physical exercise. These two topics are typified in the following discussion and excerpts.

Food has many roles in our New Zealand culture, and good eating is advocated by an endless trail of research and popular press. Participant 9 explained he was trying to alter his eating habits:

Good eating is pretty simple to follow it's just a matter of following it. [What we eat] all stems from me and my wife, whatever we've got then that's what we [plus three children] eat. We have talked about it lately actually not only for health reasons but also for budgeting because we wanted to save a little bit of money. . . first on the list was the

obvious one. . . takeaways. We don't [grocery] shop very well, we shop for two days. My wife is saying we should do a really good shop, get enough for every meal [for a week]. And then we can make healthy choices at the supermarket. (CRH9, int2, p.7)

Participant 9 knows and understands the principles behind good eating, and how to access food in terms of budget, variety and healthy choices. His answer to the question "What do you think your diet's like at the moment?" is as follows:

Bad. . .takeaways again. Maybe four nights a week. [Because we are getting home late] And everyone else is hungry [as no one has cooked]. Rather than prepare a meal we just go and get a quick takeaway. [Dinner is eaten] maybe between 6.30 pm and 8pm. (CRH9, int2, p.6)

This excerpt underscores a number of important points that other participants brought up in their dialogue. There is pressure of time, that as parents he and his wife are tired, when they finally get home to start cooking the task seems onerous, the temptation to acquire take-away food is for its convenience.

Other participants specifically targeted food that they ate, explaining it was not a healthy choice:

Well I will make sure that [my] diet gets dealt to, there are a few things in there that I should look at, well I know I should, like stopping eating ounces of butter at a time. I cook in [salted] butter, I love the taste of butter . . . just the ordinary pound of butter that you go and buy, 500 gram block [per week on his own]. (CSC8, int1, p.18)

Participant 8 chose to eat butter, it was a personal choice. He was well aware that his choice was not ideal and from his account he aimed to change this routine. In the second interview the same participant reported:

I've changed my diet quite dramatically now, to the point that I don't eat butter anymore and I haven't actually had butter in the house for a long time . . . except this last weekend when I made some shortbread. But I'm doing two things here, number one I don't cook in butter any more like I did. I use oil now and I don't particularly like olive oil because it gives me a headache. So I've used things like grape seed oil, almond oil, I've got a whole list of them. But then I like avocados. Rice bran oil, yeah all those lovely things. And I alternate because I believe everything in moderation. (CSC8, int2, p.12-13)

As participant 8 lived on his own, he could make choices about eating and a diet that worked for him without directly affecting other people in the household. He had a clear understanding that what he ate reflected upon his health. He added a further layer of blame to his butter-eating habit:

. . . obviously it was the wrong type of work [physical work at a large supermarket] or I've been eating the wrong diet for the last 30 years, my love of butter ultimately paid the price. . . it's obviously my diet because that seems to be what everyone thinks is the root cause of these problems [CVD]. And so combined with a lack of physical exercise as 10 years prior I'd been an office worker. (CSC8, int2, p.12)

The participant was well aware of the conspicuous detail (the habit of eating butter and having a sedentary job) that contributed to his current ill health. It is possible that he would have preferred that these details had remained inconspicuous, but a family history of CVD ensured this was not the case.

Participant 8 is aware of social pressures, “everyone thinks. . .”, and how this effects life routines. Participant 8 is reluctantly carried by the social pressure, knowing that sedentary work and a diet high in fat would have contributed to his current health. He had extensive discussions with his adult children about the perils of his diet (one such discussion I sat in on while he answered a phone call from his daughter in Australia during interview 1).

The socio-political pressure to eat a healthy diet is well established in New Zealand. Added to this, eating a healthy diet is often a nursing or medical recommendation that participants were offered as part of their recovery after their ACS event. The pressure to alter eating habits to reduce weight is summarised by a participant who spends up to one month a year in hotel rooms:

In terms of giving me advice about my health and my diet, find out what it is that is relevant to me and to my life situation and for someone like me who spends at least 30 nights a year in hotel rooms. When I get into a hotel room at night I usually put my shorts on and have room service because I can't be stuffed going down to a restaurant and eating on my own. What we need to do is teach the hotels to have healthier options but not just Greek salad.

Maybe you know I'll have a burger but I'll leave the bread. Give me big fries not shoestrings because I know that the big fries are better for me they're less fat absorbent than a shoestring and that sort of stuff so the advice from the dieticians in the hospital after we've had these incidents should be around hey this is a guy that's been bought up on meat and three veg all his life you're not going to change him into, you know I'll eat lettuce for my lunch every day, if it's a sandwich it will be salmon, beetroot, capsicum, tomato and lettuce. (CRG15, int2, p.7-8)

Participant 15 works in the corporate world promoting the merits of vegetables so he is uniquely placed to make the above observations. Participant 15, as did some other participants, found it difficult to eat a healthy diet because there were innumerable obstructions. These obstacles included: access to healthy food was at times unaffordable, required a demanding schedule to shop and prepare food, and living away from home sporadically meant less physical access to healthy food and less time to prepare it. The concept of eating as a life routine is beset with inconveniences, and as excerpts demonstrate, eating well required self-denial and constant dedication.

A further aspect of life routines is physical activity. Physical activity, like diet, has many social constructions that influenced individual choice and behaviours. Participant 9 reported on his lack of physical activity:

I think that I've dropped off a lot on my exercise, well I know I have. I haven't been to the gym in ages, haven't been for a walk in a long time, yeah. Just lazy . . . stuff, life, weather. (CRH9, int2, p. 4)

Participant 9 knew he had not maintained any form of physical activity and he kept his conversation on this matter short. Participant 34 had attained the complete reverse, maintaining a high level of physical activity:

The last two weeks I'm back walking properly [as had an accident] and I've got an exercycle at home I do that for about an hour at night and that started about a month ago. So mornings now I get up at 6am I do a few hours yoga and then I do an hour's walk. . . then I walk with the dog and a light jog around [the beach] that's about 4km so that's what I did this morning so that's two hours. (CRS34, int2, p.4)

The two examples above are polar opposites but emphasise how varied participants were in commencing and maintaining levels of physical activity. Physical activity is a time consuming project so was difficult for people who were time-poor, to fit this into their busy lives.

Participant 34, like other participants, seemed to attend to diet and physical activity together:

The doctor said because I'm quite frustrated at not losing any weight I think I'm fighting my metabolism now because of these the beta blockers. I know the food I'm eating is good food. I'm only eating about as much, like my wife dishes up the same portions for me and for her and she's quite slim. If I exercised the same amount 10 years ago I would have been losing weight you know and I just can't seem to lose that weight. She [the doctor] said you probably need to just give your body a shock in terms of you've got to do a bit more exercise and just watch your portions but I'm just doing a bit more regular exercise and it seems that I've lost a couple of kilos over the last month so that's pretty good. (CRS34, int2, p.5)

This seems to be a near strenuous regime, but the participant assured me that he had discussed his new training with his doctor. This excerpt does present a good example of how participants combined a strict eating and exercise schedule in an attempt to lose weight and therefore reduce risk of further ill health. Participant 34 had made other noteworthy changes to life routines, he had stopped smoking and left his stressful job. All the life routines stated were associated with wider social expectations or control. There are daily reminders in our lives to not smoke, be active, maintain a healthy diet and work-to-live. Some of the participants were considerably motivated to overcome both the external pressures of being a person who needed to change their life routines and the internal pressures of preserving this motivation. An inability to meet set goals such as reducing weight, spawned self-doubt and lack of self-esteem, all of which festered to aggravate nonattainment of goals that seemed simple enough at the outset. Some participants

that faltered, not achieving their goals, became unmotivated or frustrated and organised their lives so they did not need to confront the “existential glimpses of self” (Charmaz, 1991, p. 137).

Caring is preoccupied with participants requiring some self-interest, which can be problematic, imposing personal needs on the usual routine of a communal group such as family. Caring is also about keeping an eye on the detail, be they conspicuous (watching one’s diet or increasing levels of physical activity) or inconspicuous (the effect of taking medication). The inconspicuous and more conspicuous detail of medications is presented in the next section to extend the findings for a dialogue as caring.

### **8.2.2.2 Conspicuous medications**

The omnipresence of medications in the lives of the participants was indicative of how medications had become a major feature of the medicalised dictum. Taking medications is a conspicuous detail; this became a new or extended aspect of the daily routine. The inconspicuous nature of medications (“what do they actually do?” was a common question directed at me as the interviewer) required participants to make a conscious effort to take medications:

I don’t really like taking tablets although I know I’m going to have to from now on. I don’t know what I am actually taking now, people just rattle off all the medical names and I’m taking them because they are giving them to me and advising that this is what you have when you’ve had a heart attack and they said well you’ll be on some of the tablets probably the rest of your life and others [I] will gradually ease off them, I am quite happy with that if that’s what they want to maintain a sort of healthy life. (CJR12, int1, p.2)

Some participants, such as participant 12, were not so familiar with their medication, and were happy to leave the technical detail of what they were taking and how the medications worked to others. When participant 12 was asked what he knew about his medications his reply was lacking confidence, at which point his wife intervened:

Wife: The chemist lady did come in this afternoon, the pharmacist and she explained everything, she did say. She told you all the drugs that you would be on.

Participant: You know if you can’t actually see them down in writing it’s very hard just to [know], if you’re not attuned to medical terms for a layman it’s a bit hard to remember exactly all the [names]. . .to pronounce some of them you’ve got to really read it off the sheet. (CJR12, int1, p.3)

Working together, as participant 12 and his wife did, to comprehend the necessity of medications in their life, accommodating the administering of medications into life routines was a common pattern found throughout the interview data. It was revealed that participant 12 had had the same information repeated to him on a few occasions. This last excerpt raises two

important points for patients with acute illness. The repetition of technical information is invaluable to patients, and having a support person available is key to maximising comprehension of all the information people are exposed to in acute hospital settings. In order to hold the interest and motivation it is essential to write down or provide written material as participant 12 suggested. The above excerpt is from an interview in hospital when as patients, participants were often tired. The following excerpt is again of participant 12 at interview 2:

After the heart attack I was absolutely inundated with information about medication, food and you know all that sort of thing. So if there's any other issue that comes up I mainly just copy it into the computer and you can read all about it, it's a bit scary. So generally I haven't really got a source of information apart from what is [handed out]. (CJR12, int2, p.14)

I take simvastatin<sup>11</sup> at night, in the morning I take four pills, Betaloc, an aspirin which is 100mg. I take pantoprazole<sup>12</sup> which is 20mg. I take cilazapril<sup>13</sup> which I think . . . 2.5mg. The simvastatin is 80mg, the Betaloc is 47.5mg, and the cilazapril is 2.5mg. (CJR12, int2, p.21-22)

The participant had made great efforts to become more acquainted with the polypharmacy he was asked to take by his doctors. It is interesting to note that in interview 1 he seemed to not wish to know what his medications were and yet in the second interview he had absorbed the medicalised or technical aspect of pill taking into his daily routine. The conspicuous nature of not knowing about his medications is less conspicuous, taking medications became a visible feature of his daily routine.

Taking medications is an example of conspicuous (visible) detail; many participants were quite focussed on routines of medication taking. On the whole participants took their medications; they became an important part of their daily routine, had a physical presence in kitchens and bathrooms, computer bags and handbags. Participants went to their doctors for further prescriptions, had their blood or blood pressure checked because they took certain medications, visited their local pharmacy, organised their medications into blister packs, had some knowledge of nomenclature and effects, forgot to take medications, and spent extensive energy avoiding them or ensuring that they were a fixed part of daily schedules. When participants were asked what effect the medications had a number could not confidently explain their various actions, hence the inconspicuous detail of medications. It is not like wearing a fibreglass cast around a fractured bone, where it is clear what the cast achieves. Many participants had insights into statin medications, "that Simvastatin is a cholesterol tablet" (CJR12, int2, p.21), and antihypertensive medication "I've got cilazapril and that is for my blood pressure" (CMR17, int2, p.24). It was noticeable that even if participants did discern a little of the effects

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<sup>11</sup> simvastatin: treatment of hyperlipidaemia, hypercholesterolaemia

<sup>12</sup> pantoprazole: proton pump inhibitor, for treatment of duodenal and gastric ulceration

<sup>13</sup> cilazapril: ACE inhibitor for treatment of hypertension

this needed to be teased out with them. The two examples in the previous sentence required questioning such as “what does it do to your cholesterol?” and “what does the medication do to your blood pressure, does it bring it up or down?”

Some participants were familiar with their medications. Participant 2 illustrated a particularly thorough understanding of his medication:

*Kim: But the other problem that you had this time round when you were on metoprolol?*

Participant: the Betablocker was a very much reduced dose because they were aware of the history [of bronchoconstriction] and the doctor yesterday suggested that that was the cause of asthma like symptoms that were making breathing difficult.

*Kim: [You were] getting a lot of breathlessness yesterday? . . . do you think it had got worse since you had had the metoprolol?*

Participant: Very definitely so yes . . . I couldn't really judge it because it was sort of the pain from the heart going away while this other one [pain of bronchoconstriction] was coming on and both in the chest area. (CPC2, int1, p. 3)

The participant knew exactly what aspect of health care had become conspicuous, the bronchoconstriction brought on by beta blocker medication. He had a highly medicalised construction of illness focussed on various aspects of medications: how they related to his body, how they related to other diagnoses, what side effects may be expected, and what to do about side effects should they occur.

A further participant reflected upon the medications he should have been on and was convinced the reason for his chest pain was that he had not been taking diltiazem<sup>14</sup>:

I think this is one of the problems I had having this diltiazem dropped because I don't know how it happened, if I go to the GP she will say oh well you didn't give it to me on your list which I most probably didn't but she should have picked it up on the computer . . . it wasn't until I was doing my tablets the other day, I break them in to a week lot but I had all this diltiazem over so I rang the pharmacy and she said no you haven't had them since August, so that's two lots of scripts that I've missed so I am just wondering did that bring on the angina? That's my theory . . . I might bring it up with [cardiologist], I get more out of him, than with the GP . . . I would mention it to her, I would like to know. As I say . . . I write the list out for her and she's got it on the computer, she should have said well look there's no diltiazem down here, and I can't remember anyone saying they were going to take me off it. (CDW13, int1, p.9)

Participant 13 was finally put back on diltiazem with the effect of reducing his recurrent angina. His embattled account shows how participants-as-patients needed to work hard at making sure that their health care (caring) was optimal. The participant was sufficiently astute to fathom the problem as he had been living with complex illness for some time and his experience alerted him to the problem of the missing medication. It was this openness to the conspicuous and more

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<sup>14</sup>Diltiazem: calcium channel blocker, used to medically manage chronic stable angina or angina due to coronary artery spasm.

inconspicuous detail that ensured some resolution of disequilibrium. This example shows how participant 13 had become attuned to and controlled aspects of his complex illness. With control came the ability to reason and thereby “self-advocate” (Charmaz, 1991, p. 285). Participant 13 would have thought through possible reasons why his angina had accelerated and traced it back to the lack of diltiazem in his medication blister packs. That he considered asking the cardiologist about the missing medication in preference to the general practitioner shows further incisive critical thinking and autonomous decision making.

The conspicuous nature of medications in the retold experiences of the participants highlights how pharmacological interventions became a major aspect of medical care, to fix aspects of illness. Taking medications is a conspicuous detail of the “body-as-machine model” (Oakley, 2007, p.91), with emphasis on function and less on the sensibility of the experience of illness.

Medications were taken to reduce risk or threat of evolving illness. The aim was to reduce risk of high blood pressure, risk of clotting, risk of heart failure, risk of progressive CVD, risk of further physical dysfunction living with the living body. The topic of taking medications links well to how risk was managed by participants. In part, the taking of medications is to avoid or reduce the risk of dyslipidaemia or hypertension and the consequences that may follow. The following section attends to the dialogue with participants to identify, act upon and even include risk in constructions of illness.

### **8.2.2.3 Conspicuous risk**

Some aspect of risk was discussed in all interviews, as participants grappled with why they were hospitalised and how they could curtail CVD if not eradicate it. The following is an excerpt demonstrating how risk was usually introduced into the conversation. The conversation was steered into a more general topic of family history of hypertension, CVD or diabetes and how that dovetailed with risk, as medically recognised risk factors. I asked participant 10 if they understood why they were on anticoagulants and why they remained on aspirin:

Participant: I'd stop it [aspirin] if I weren't too scared of the stroke . . . if the blood is a bit thinner it will pass around [with more ease], pass through the heart around the body a lot more quickly and easily . . . and it's not going to clot as badly.

*Kim: Then there is less risk of having a stroke?*

It's the stroke I'm terrified of. They're caused by a multiple of things I mean you can have a stroke through losing blood or a heart attack but from my families point of view it's mainly the hypertension. . . and my grandfather died of it and it's right through the family [as a risk]. Hypertension and stroke . . . my mother's family. (CDM10, int 2, p.10-11)

This is an example of the type of conversation I had with participants, the participant begins by talking about their medications, as the researcher I tried to ask why there may be a need for (some) medication. Participants such as participant 10 quickly linked prophylactic medications with the hope of avoiding risk of further ill health, even avoiding death (although this was not verbalised consistently by participants). There was substantial concern about becoming severely debilitated, “It’s the stroke I’m terrified of”, as participant 10 states in the above excerpt. The constant fear of potential disability drove some participants to incorporate medications into their daily routines, to counter risk.

Many risk factors were revealed or targeted during the interviews. As an example participant 9 was asked if his family members had any medical problems, his reply was:

My brother’s got diabetes but he’s done a lot of with it and he’s really good now. I think he’s on the pill. We have an overweight problem with our family . . . basically all of us. My mother was diabetic and my father he was healthy except for his heart attack (CRH9, int1, p.14)

Participant 9’s parents no longer lived, they both died in their mid to late sixties, his mother had diabetes, his father had CVD. Participant 9 played down his father’s ill health, that he was healthy except for his myocardial infarction; it was not clear what other comorbidity his father had. Participant 9 did not verbalise the link his family history had to his own health in either interview. It was only after we finished interview 2 that he assured me his family doctor had explained that he had a number of risk factors: a significant family history and his ethnicity as he was Māori (Reflective Account, 30 November 2010). Risk was a conspicuous detail that evoked fear and/or motivation to cooperate with the restrictions imposed by the medicalisation of the lives of participants.

Participants identified conspicuous risk and what changes had been made to improve health in the same conversation. As an aspect of daily routine was altered, so too was the risk of aggravating ill health or accelerating to further ill health. Participant 15 enjoyed a drink of whiskey; however at our first interview (about a week after discharge home) he mentioned that he would have to alter his alcohol intake. When we met at the second interview participant 15 had made an effort to lose weight, so I asked him how he achieved this:

Basically I’m not drinking the same amount of whiskey I’m drinking a lot less whiskey. I’ve possibly been eating less food, I’ve been watching as a generalisation what I’m eating for my lunch. I’m pretty sure [his wife] is actually trying to give me less food on the plate. I’m exercising, I always have been reasonably diligent in my exercising but I’ve been pushing myself a little bit, trying to push myself a little bit further every day well not every day. (CRG15, int2, p.4)

All these changes to his daily routine were from discussions about how life needed to change, restorative dialogue and caring were evident. Nowhere was the word risk used, it seemed invisible. For example he used a phrase “conscious decision to myself” to accentuate that he had been mindful about why he was making a change to his daily routine. A further point to note was that this participant, like many others, had a source of motivation:

I made a conscious decision after I had this incident that I had a one year old grandchild and if I wanted to see his 16<sup>th</sup> birthday I was the one that had to make lifestyle choices, not him so I’m conscious of that. (CRG15, int2, p.5)

People were faced with confronting mortality, making important choices around whether they wanted to live or die. The interpretation that participant 15 had arrived at in this last excerpt was that he chose to work with and counteract the risks where possible, particularly as he had a new motivation to avoid death, to watch his grandson grow up. The participant had turned inward (Charmaz, 1991) to consider what was important to him. Death seemed less visible as risk was countered by activating modalities against risk.

Participants required information to make wise choices to avoid risk. The following section regarding information is concerned with how and why participants accessed and used information to assist in living with complex illness.

#### **8.2.2.4 Information**

Participants were consistently building upon their understanding of CVD and prediabetes by sourcing information about the various aspects of their complex illness. This was demonstrated in the language participants employed, the confidence they demonstrated in the use of highly medicalised terms describing their condition. Information came from limited sources.

Participant 18 explained that he tended to ask his doctor for information:

It would be the doctor . . . occasionally [a magazine or paper] you know you might come across an article in the newspaper about something that’s been discovered but I don’t go fishing for information about health, I don’t go seeking it out anywhere. With the constant or shall we say regular monitoring of blood pressure, if I have got any questions I could ask the doctor cause I see him every six months or so. (CDH18, int1, p. 14)

Another participant explained he too attended his doctor for information as well as using the internet:

Doctors, internet or we do have a lot of first aid books. I mean I’ve got a big book at home it’s called the medical encyclopaedia sort of thing and it tells you, it came from readers digest and it tells you symptoms of you know a lot of your most common problems and diseases and all that sort of stuff there and what you can do to help to alleviate it.

The stuff on the internet yeah we like to go and look . . . for example our flatmate downstairs I think she gets hypoglycaemia or something, I don't know what it is but we had a look on the internet for her and my God there's bloody pages and pages of the stuff so we're going to try and go in to it a little bit deeper you know and have a look. I mean there is a heck of a lot of information there and also not only that there's a lot of bloody garbage information out there so you've got to work out which one is the bloody proper one. (CAH25, int1, p.9-10)

A further participant accessed the internet, but explained there was a great deal of misinformation:

I have been known to go onto the internet. . . John Hopkins sometimes and just different sites. . . you just read things and I know full well that half of it I probably don't understand but the urge to know what's going on takes you there and to be blunt, it's free, which makes a big difference. Otherwise I talk to the doctor, obviously, I talk to [the family doctor]. . .to you [the interviewer].  
I got put off [books] when I had my first bout of cancer and walked into a bookshop and picked up a book which said "Oh, people with what you've got usually die quite quickly" and I thought I don't think you should read medical books [participants name]. I think you should go and see people who've read them and understand them . . . books and the internet have no empathy, so what is there is there but your interpretation of it can colour the information that you're given. Whereas if it's given to you by someone who really knows and even knows you . . .(CRW7, int2, p.23-24)

Participants were keen to access information, with the caveat that it needed to be reliable. Surprisingly few participants used the internet regularly for information about their illness (including the younger participants). Overwhelmingly the doctor was a primary source of information. Participants were asked if they spoke with the practice nurse for information to which a number acknowledged that the nurse was also a resource they used regularly.

Information is more than the material available on internets and from informants such as health professionals. Information helps bring about understanding that is beyond technical know-how. Gadamer writes:

As a phenomenon of lived experience, insight into one's own illness is clearly not simply insight in the sense of knowledge of a true state of affairs, but rather, like all insight, it is something which is acquired with great difficulty and by overcoming significant resistance (Gadamer, 1993/1996, p. 52).

Gadamer's words help reframe the extent of the information that participants were hoping to find, they were seeking out knowledge that could not be found in doctors' offices or the internet or books. They were in the midst of experiential learning, taking experiences and extrapolating them to constructions of knowledge. Participants were seeking a kind ear and voice to confirm that illness is difficult. Gadamer writes further:

It is clearly a misrepresentation of the phenomenon to look at the concept of illness solely through the eyes of the doctor and from the standpoint of scientific medicine, and

to think that medical knowledge is the same thing as the patient's own self-understanding (Gadamer, 1993/1996).

Through the process of seeking information perhaps participants were not always seeking cold hard facts, more a personal insight, an extension of what Gadamer calls self-understanding, as becoming aware of the visible "a landscape, a topography yet to be explored" (Merleau-Ponty, 1964/1968, p. xlvii).

### **8.2.2.5 Caring for self**

Participants in this study made decisions about their individual care. In this study caring for self involved an active process of "recovering, maintaining and improving one's health" (Ziguras, 2004, p. 3). Participants learned to become aware of the less conspicuous detail and work with the more conspicuous detail. This is a dynamic process wherein experiential learning about the body and mind helps gain insights that contribute to caring for one's self.

An example of caring for the self is how some participants learned to treat their chest pain.

Participant 4 had been experiencing angina for some time, but only a week before his cardiac arrest and subsequent CABG surgery he was seen by a specialist to confirm his CVD.

Fortunately he had had a discussion with a friend who also had some experience of angina:

I was told by a friend of mine who has angina, he says they will give you a puffer [GTN spray]. I was just starting to find out through the doctor [about his angina] and [the doctor] said they will give you a puffer, when the pain comes on your chest, have a puff. But if you know you're going in the garden to work have a pre-puff first and then go out [to do the] gardening. It's a bit better that way he said, but if you have to puff twice and it hasn't gone away he said pick it up and huff huff and if it hasn't gone away a third time call 111<sup>15</sup> and that's what we did. (CEH4, int1, p.2)

This participant was fortunate that he had recently seen a cardiologist who had already alerted the general practitioner that there were concerns about his health. It was also opportune that the participant had had a conversation with his friend to substantiate the routine of using GTN spray in three cycles, and if this failed to relieve the pain that emergency services be called. In terms of caring for the self, this excerpt shows indirectly how self-assessment of the chest pain will have instigated the use of the GTN spray. What is clear from the excerpt is that the participant cared for himself by trying out the GTN spray and then quickly realised that he needed more intense care. His self-care did not fail, if anything he saved his own life by taking note of the conversation he had with a friend.

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<sup>15</sup> The New Zealand emergency service call centre

Participant 34 provides a further example of caring for self by ensuring he has his GTN spray with him at all times:

I carry it [GTN] with me because I go out to quite remote places and so when I take my dog we go miles down the beach and I'm the only person there so always take my cell phone and the spray. (CRS34, int2, p.10)

This shows caring for self, a proactive task of always carrying around the GTN spray, a constant companion. The participant had a strategy, "I always take it with me" (CRS34, int2, p.10) even though he never seemed to need it. Caring for self with illness is concerned with not taking chances. As detail becomes conspicuous (that chest pain is a potential event at any time) a plan is constructed so in the event of developing chest pain, this can be acted upon.

There were many examples of caring for the self as expressed by the participants, supported by a remarkable range of projects and habits. Participants came to know their bodies well and felt frustrated when attempts at caring for the self were ignored or even considered ill-informed. Participant 33 spoke of an incident which involved the replacement of an intravenous (IV) cannula:

I had a problem with one of the nurses and I said to her I know what to do [where to re-site the IV cannula] so I just basically told her what to do and she wouldn't do it and I argued with her and told her to go away and said get me another nurse and she [new nurse] came in and we did it together. I thought you know the patients do know some things and we know our own bodies and we know what's happening with our own bodies. (CWA33, int2, p.4)

Participant 33 has a tendency to develop cellulitis, and had had numerous episodes of administering intravenous antibiotics at home, which involved working with the local community nurse from the regional hospital. As a consequence his peripheral veins had become fragile and had become well informed about the anatomical and technical detail of reinserting intravenous cannulae into his veins. The participant knew exactly what was required when the same situation arose in hospital after he had had a myocardial infarction. He was saddened that the first nurse inserting the cannula had little insight that he as the patient would know how best to approach the task. As he said "we know what's happening with our own bodies", that people do understand complex problems and strive to be able to resolve problems for themselves. The first nurse perpetuates the notion of professional control, not conducive to caring for self.

This subtheme is instructive of the important "skill of balancing [which] is precisely intelligent behaviour" (Gadamer, 1993/1996, p. 55), the planning and effecting of caring for self. In the following section (8.2.3) the intelligent behaviour as Gadamer describes, is concerned with how participants came to understand their state of illness by attending to detail. Constructing an

understanding of illness emerged from dialogue and caring as intelligent behaviour, revealing living with complex illness.

### **8.2.3 (Re)constructing illness**

In Chapter 6, Section 6.5.3 the subtheme (re)constructing illness was described as a dynamic process wherein participants perpetually reconstructed their understanding of illness. This is an iterative process dependent on the passage of time, experiential learning coupled with self-awareness, in turn creating new meaning. There is no one definitive meaning or truth that serves as a universal construction of illness. Each participant had their own focus on particular detail that contributed to their own personal construction. This conception is ontologically crucial to the theoretical perspective of this doctoral research, that there are multiple realities (section 3.3.1), which epistemically denotes that participants have their own constructions of what illness is for them.

The subtheme (re)constructing illness has three embedded subthemes. These embedded themes are: new constructions of illness, recognising well-being in constructions of illness and constructing complex illness. Each embedded subtheme is introduced with supporting excerpts from the interviews.

#### **8.2.3.1 New constructions of illness**

Three participants (6, 20 and 30) have blood test results that indicate they have type 2 diabetes. These three participants talked about this new diagnosis in their second interview.

Participant 20 explained that the diagnosis of type 2 diabetes was not really new to him:

It was [the general practitioner] that told me that first, and I didn't think anything, he just said well you know watch your diet . . . that was six years ago I think. Well [you telling me I have high blood glucose] that's not news. (CDP20, int2, p.12-13)

Participant 13 had blood results that showed he too had type 2 diabetes:

*Kim: you've got quite a high blood glucose*

Participant: Nobody's ever told me.

*Because that's the whole point of you being in this study as well.*

So there's no diabetes is there?

*Well no it's not frank diabetes but you're certainly in a grey area where they want to keep an eye on it.*

Well who does that, you or?

*Your General Practitioner*

And she knows about this?

*Well I'm going to [ask someone to] write her a letter. (CDW13, int2, p.21)*

Participant 13 was not aware his blood results indicated that he was borderline type 2 diabetes. Even though his results were sent to his general practitioner, it appeared no conversation had been entered into with participant 13 about his high blood glucose. His construction of illness at the time did not include a diagnosis of high blood glucose. His construction of illness was more focussed on being alone, caring for a wife with dementia and managing chest pain when it occurred. These aspects of his life dominated a good portion of his interviews (both 1 and 2). His construction of illness was concerned with “the private face of a public problem” (Charmaz, 1991 p.4). To understand people’s new constructions of illness, there is less detail required of physical function, more of learning about the detail of the person’s experience.

Participant 17 had a very different experience which required her to reconstruct her understanding of illness a number of times. Recall participant 17 from Chapter 6; excerpts were included from interviews to represent embattlement in section 6.4.2. The participant had CABG surgery which was followed by the discovery of a cerebral aneurysm approximately eight months after cardiac surgery. An excerpt from the second interview illustrates the start of a new construction of illness when discharge home was suggested:

I had to have the stimulation from home [she went home for a home visit] and realised that this was where I needed to be. And although there was an awful lot still, I couldn't remember a lot and there were things like I wasn't talking, I wasn't speaking very well to people, but the nurse said to me that night, “I'm going to suggest that you go home and don't go to [the rehabilitation ward]. You are far too good to go [there] and I think you'll do much better at home.” She said, “The change in you today has been phenomenal and you're only going to get better.” She said, “I'm going to speak to [the occupational therapist] . . . and he can talk to the doctors.” So when he came back after the long weekend he couldn't believe it. He said to me, “No, you're going home. Can you get someone to come and get you today?” and I said, “No, it'll have to be tomorrow,” and in walked my sister. And I said to her, “Can you take me home?” and she said, “Of course I can.” So that was it and I came home and never really looked back from that day. (CMR17, int2, p.28)

The participant endured two serious conditions over the course of one year. Motivation was instilled by the uplifting positive comments made the nurse and occupational therapist. A new construction of illness included her home, and even though there was memory loss and poor speech, confidence was sufficient to trial life at home. The constructions of emerging health were influenced by the health professionals that participant 17 worked with; they persuaded her that the home environment was ideal for her to grow positively from her experiences, not the rehabilitation ward.

New constructions of illness are about the intercept of function and experience. A further aspect of this intercept is how experience impacts upon well-being. The following section reveals how participants did have well-being amidst living with complex illness.

### 8.2.3.2 Perceiving well-being

Well-being refers to a state of “not noticing” (Gadamer, 1993/1996, p. 73), a construction of health which is not consciously noted. This is slightly contradictory, labelling this glimpse of “not noticing” as perceived well-being so we are conscious of things that are not always in our daily thoughts. None the less, well-being is an inconspicuous detail until the focus of conscious thought renders “not noticing” visible.

“It is only now, in its [health] absence, that I notice what was previously there, or, more precisely, not *what* was there but *that* it was there” (Gadamer, 1993/1996, p. 74), this is well-being. This state of well-being lends itself to being less tangible:

Well I’m feeling good you know, I’m feeling energetic, yeah, I just feel a general sense of well-being really. (CRS34, int2, p.1)

The participant explained that he was energetic, and yet there was a sense of something less perceptible, the “not noticing” i.e. this participant is referring to what Gadamer terms “that it was there” rather than “what was there” (in the above Gadamer quote). The question was posed as to why the participant thought he had a sense of well-being:

Well I’ve got no pains or I feel quite fit, I feel like I can walk and run and do things that you know I could do 20 years ago, I’m doing quite a bit more exercise now and I’m losing a bit of weight, I’ve given up smoking, I’m eating a good diet and just generally feel quite good. (CRS34, int2, p.1)

Participant 34 had worked very hard at recuperating from a myocardial infarction. He repeatedly mentioned he “feels” in the interview to assure himself that indeed he was describing his experience rather than function. He was standing still and noting “I feel . . .” This was part of noticing his state of well-being, a state of “not noticing”, detail becoming conspicuous, of itself contributing to a reconstruction of illness.

An additional excerpt provides insight into the absence of well-being in the construction of a participant’s illness. Participant 13 explains:

I think I sort of washed myself out by going to see my wife [who lives in care as she has dementia]. Although I drive in and there’s no great effort up there but I think seeing her like she is and the other people it sort of has an effect on me. A tiring effect . . . I just come home sometimes, I tell my daughter, she says what have you been doing? I say I’m exhausted. [He visits her] twice or sometimes three times a week. It’s a conscience

thing if I don't go it builds up and if I come in to town I must go and see her. (CDW13, int2, p.2)

The illness of his wife had a significant effect upon his well-being. Living with her illness affected how he lived with his own illness. He noticed 'that it was there', how he is tired after visiting his wife. Even though this participant did not use the words well-being, his perception of well-being is reflected in the effect the intercept of function and experiences had on his life.

Participant 30 provided an excerpt demonstrating he believed he had well-being even though he had just had a large myocardial infarction followed by CABG surgery:

I think personally myself, you just focus and actually evaluate your existing life, because there's not many events in a person's life where you actually do look and step back and say, "okay, that's the way I am, that's what I want to do" Like for example, if I didn't have a heart attack or major surgery I would just continue what I was doing [working very hard] that's the way it is, and I wouldn't know any better. (CRY30, int2, p.28)

The participant was reflective about the events of the past ("look and step back"), he expressed concern for his existential being ("that's the way I am"), that something positive had come from his hospitalisation, he had taken time off to recuperate and consider his future, considered the whole. Throughout the entire second interview the participant seemed much more reflective than the first interview. This thoughtfulness mirrored his well-being. Participant 30 was at the commencement of a reconstruction of illness which was likely to go through numerous modifications. Reconstruction involves a "genuine consciousness of the problem", understanding how one is no longer "being unhindered", making sense of new experiences to assimilate with "the whole" (Gadamer, 1993/1996, p. 73, all short quotes).

### **8.2.3.3 Constructing complex illness**

As a group, the participants had a range of variables that contributed to complex illness. The scope of variables that were instrumental were: temporality, the sequence of events leading to and maintaining ill-health, and individual contexts of participants. All these factors spawned complex illness as a function of: personal experience (including psychosocial and physical aspects), experiential learning, temporality and perceptible illness. As an interpreter, I observed and came to know how participants constructed and understood illness, as they came to know of the conspicuous and less conspicuous detail of their lives. For this reason, complex illness became greater than the experience of a medical diagnosis.

Complex illness is about understanding and synthesising what personal needs are in terms of coping with illness plus life and living. An example of an aspect of life and living that participants dwelled upon was the need to work (paid or unpaid). Interviews demonstrated: deciding to resign from paid work (CSC8, int2, p.5; CRS34, int2, p.4), carrying on with their jobs with awareness of physical limitations (CPK31, int2, p.20; CDP20, int2 p.28; CAG21, int2, p.6; CNB23, int2, p.1; CHC28, int2, p.9; CDH18, int2, p.21), and uncertainty whether to return to their former working position (CJG16, int2, p.4). This was but one aspect of life and living that participants indicated to be part of the discussion of complex illness.

The following are three different representations of complex illness from participant interviews. These interview excerpts help further refine and interpret what complex illness is.

Participant 8 began interview 2 by answering the question “in general would you say your health is?” options being poor, fair, good, very good or excellent. The participant replied “good” and when asked why he explained:

Participant: Because I’ve had a heart attack [2010] and I’ve had a brain tumour [2007] so my health isn’t perfect so that’s the two reasons why I’ve put it down as good. After my heart attack I can only work for about an hour to two hours at a time before running out of steam or get tired. So from an activity, physical activity point of view I can’t do it for eight hours like I used to when I was 20. With my brain tumour my short term memory went and I just blamed it on getting older but in reality the brain tumour squashed the short term memory part of the brain. I should have more energy than what I’ve got. It’s just one of life’s little things that gets thrown at you, you know you just deal with it and work around it.

*Kim: So how have you dealt with memory issues?*

Well I’ve dealt with it by . . . mum died three months ago so I moved in to her house at [the beach] and I just do gardening now and walking along the beach . . . nice challenge of watching things grow, getting her garden back in to some semblance of order, getting vegetables growing again which is physical as well as mental ‘cause it conditions you at that point. And then once I feel a lot better I will get back in to a job of some description again. [Will take] a year, another year probably, it’s a bit open ended really. It’s you know if it doesn’t happen it doesn’t happen, I’ll just continue doing what I’m doing.

[Finding a local doctor] I’d much rather spend the hour travelling to see my GP<sup>16</sup> down here because I wouldn’t get in to a practice up there cause there’s about 1500 people waiting, new patients waiting for doctors up there.

[Currently still unpacking belongs in the beach house] So it’s conflicting time you know time things happening. And that’s all very energy sapping at the end of the day, living in a mess [unpacked boxes] is quite energy sapping in itself. I don’t have that much energy today I won’t do anything.

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<sup>16</sup> GP = general practitioner

[While working before myocardial infarction] I was working a 40 hour week. That was just full on stacking shelves, making sure they're full in the fresh market. I actually finished, after my heart attack, I never went back to work. I just had that and then basically went on sickness benefit really after six weeks. The doctor said "sorry no lifting boxes above your head. Because too much of a strain on your heart" So he very, very strongly urged me not to because that was part of it, was lifting boxes of 24 cans up above my head, pulling stuff down off ladders, etc, etc and puts too much strain on your heart. No stayed off for that six weeks and then I just handed in my resignation.

My mum had been sick, she had terminal cancer. She was going to [a regional] hospital which I don't totally agree with what they did. Well I think if she'd been down here [Wellington] things might have gone a bit different. Just the slowness of doing anything, you know she ended up with a surgeon who promised her the earth and delivered peanuts. It had been identified and then after six months, they decided to do some radiation chemo on it. (CSC8, int2, p.1-6)

This large excerpt shows how a number of then current issues interplayed: his prior illness (brain tumour), his capacity to work in his previous job, coping with the death of his mother and trying to find his space in the old family beach house now his mother has died. Added to this is a layer of physical incapacitation and gradual recuperation from a myocardial infarction. In the large excerpt above there was no mention of his condition, that of CVD, a high blood glucose or prediabetes. Only when the participant was specifically asked did we have a brief discussion about his high blood glucose.

Constructing complex illness for this participant included the following factors: being aware of his lack of short term memory capacity, being aware of his physical limitations by avoiding heavy lifting particularly above his head, becoming frustrated with health services for his mother while being treated, coping with a dying mother, coping with bereavement, becoming frustrated with the lack of health care in his new local community, becoming frustrated with the lack of physicality and stamina he had, changing his living arrangements (moving to the beach), planning a future, planning how to reignite his well-being. There are likely to be many more factors that contribute to this melange, in its current form this list directs the reader's attention to 'the whole' (Gadamer, 1993/1996). The whole concerns the visible and the invisible (Merleau-Ponty, 1964/1968) and the space between, as the in/conspicuous detail of complex illness.

Participants talked about their illness as comorbidity, which in itself created complexity for the participant. Participant 13's second interview provided useful aspects of life and living counter balancing the diagnosis of type 2 diabetes. He described how he coped with seeing his wife in care:

I think seeing her like she is and the other people [other patients in the care facility] it sort of has an effect on me. (CDW13, int2, p.2)

In the preceding section (section 8.2.3.2) there was an excerpt portraying Participant 13's well-being. He was finding the pressure of needing (his own choice of enforced need) to visit his wife was affecting his well-being. It was likely that he was depressed about his wife's poor health and this in turn affected his own health. Added to this, he had sustained high fasting blood glucose. It was not clear from our conversation if his general practitioner has talked with him directly about this diagnosis:

*Kim: you've got quite a high blood glucose?*

Participant: Nobody's ever told me. So there's no diabetes is there?

*Well no it's not diabetes but you're certainly in what I would call a grey area where they want to keep an eye on it.*

Well who does that, you or?

*Your GP.*

And she knows about this?

*Well I'm going to write her a letter . . . has she ever discussed it with you?*

This is the first time you mentioning it. I do eat a lot of sweet things so if that's got anything to do with it, but I have cut back on all sugars lately because of this development.

*See your fasting blood glucose was 7.4[mmol/L] and that's high, you've got an HbA1c of 6.3[%], [44mmol/mol new units] and that's high too.*

There was one time they rang me up and said they wanted another blood test [the result was still high] So I went back [for a blood test] but I never heard anything about it. (CDW13, int2, p.21-23)

The main point from this excerpt is that participant 13 seems confused about which blood test was taken for what purpose, information important to his understanding of complex illness. The blood results: fasting blood glucose = 7.4 mmol/L and HbA1c = 6.3% are both elevated according to the New Zealand Society for the Study of Diabetes parameters (please see Appendix 1), indicative of diabetes. The conversation was tempered by ensuring that a letter would be sent to his general practitioner to revisit his high blood glucose. My role of clinician and researcher were again blurred as it seemed the participant was unclear about his status. It was possible that the general practitioner was attempting not to alarm participant 13 and may be taking a series of further blood tests to confirm his high blood glucose, which I had no knowledge of. The decline in physical state and well-being of the participant did not assist him in grasping the complexity of his illness, and this was made more problematic by the lack of information exchanged by patient and health professional.

Participant 13 demonstrated his willingness to allow health professionals to oversee his composite illness during the two interviews. He was just coping with the issues of his wife's ill-health and therefore delegated the care of his complex illness to others. Having a high blood

glucose was new to participant 13, and although he was not familiar with this detail yet he seemed to understand that a blood glucose level is affected by what you eat:

Participant: So what's the glucose brought on with, eating sugar or?

*Kim: Yes can do, but not always*

Pavlova's, I think I told you that the nurse [while he was in the cardiac care unit] came in the middle of the night with one and we scoffed it. I thought to myself should not have done that. Mud cakes were cheap the other day and I bought one. . . I shared it with other people. . . I really have cut down sugar I used to have on my porridge and you know I've cut back on a little bit now, I can eat my porridge without sugar. (CDW13, int2, p.23-24)

At the start of the excerpt he was checking that high blood glucose was brought on by "eating sugar", and then explained he had a sweet tooth and had eaten sweet cakes (Pavlova and mud cake). He then told me that he was trying to reduce his sugar intake, trying to convince me (and himself) that he was making efforts to care for himself. The excerpt highlighted his diminished self-confidence and genuine attempts at self-denial to limit his sugar intake. He recognised conspicuous detail (high blood glucose), alluded to inconspicuous detail by reporting his reduced sugar consumption. The less conspicuous detail was concerned with self-denial (cutting back on sugar when he still would like sugar on his porridge) and control in caring for self.

Participant 13 also experiences significant bouts of gout:

I get gout, terrible painful feet and I live with that and I'm always interested in what my uric acid levels are. I'm on allopurinol<sup>17</sup> and I don't think it does much good, I'm very tempted to go off it for a while and see what happens . . . well it took a long while to kick in, I must have been on it six months and there was no change whatsoever. A friend of mine gave me a list of things not to eat, well you'd starve, just about everything is covered. It was even green beans of all things. I grow them, I eat them raw and oh goodness I'm going to get a dose of gout from this but if you read what not to eat you'd starve. (CDW13, int2, p.27)

Participant 13 explained his understanding of a physical process and what may result should he stray from the medication routine, that certain foods would initiate gouty pain. What was of interest was his familiarity with his old diagnoses and subsequent caring for self, explained as "I live with that". Perhaps adding prediabetes at that time tipped the balance of coping, 'the whole' was too overwhelming to manage in an immediate reconstruction of illness.

Constructing complex illness is a life's work of coping with and adapting to an intersection of in/conspicuous detail. The possibility of the invisible undermines the visible, this in part being dependent on risks patients as people are willing to take in terms of decisions made in caring for self. Constructions of complex illness are the patients' understanding of life as lived by them as

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<sup>17</sup> Allopurinol: xanthine oxidase inhibitor, for gout.

the person experiencing illness, they are not constructions enforced by others involved in the dialogue as caring.

### **8.3 Conclusion**

Chapter 8 has examined in detail the second major theme dialogue as caring. Three subthemes restorative dialogue, caring and (re)constructing illness have highlighted how participants further interpreted attributes of illness. Restorative dialogue had embedded subthemes dialogue for sharing burden and medicalisation of detail which both exemplified how the restorative dialogue develops. The subtheme caring had embedded subthemes life routines, conspicuous medications, conspicuous risk, information and caring for self. These four embedded themes highlighted the enormous variety of planned and unforeseen activities activated by participants while coming to understand illness. The subtheme (re)constructing illness also had embedded subthemes: new constructions of illness, perceiving well-being and constructing complex illness. These last three embedded subthemes revealed further the very demanding lives that some participants abided because of the complex nature of their illness.

## **Chapter 9**

### **Discussion**

#### **9.1 Introduction**

The composite nature of complex illness has been explored in this study, for those with cardiovascular disease and prediabetes. The methodology utilised to reveal the complexity of illness was interpretive description (Thorne, 2008) informed by Gadamer (1960/1998, 1993/1996) and Merleau-Ponty (1964/1968). Participants were asked about their experiences and interpretations of illness. Thirty three participants were recruited at a local Heart and Lung Unit. Data were obtained from these 33 participants mainly by two open-ended interviews, one immediately after the acute coronary syndrome event (where possible while hospitalised), and a second interview approximately 9 months after discharge home.

Research findings about living with illness were related to understanding what Gadamer describes as “the whole in terms of the detail and the detail in terms of the whole” (1960/1998, p. 291). The detail as in/conspicuous are reflected in the thematic framework (Chapter 6) which was constructed to summarise and organise the interview data into themes to reveal complex illness as experienced by the participants.

The purpose of this chapter is to reflect upon the research methodology, interpretive description, used in this project (Section 9.2). The principal findings (Section 9.3) are also discussed as is a summary of the research findings (Section 9.4). The chapter provides a discussion of risk in the context of this research (Section 9.5) and an exploration of self-care in constructions of complex illness (Section 9.6). Complex illness as an experience of ‘the whole’ (Section 9.7) is also presented, as are study implications and recommendations (Section 9.8), and study limitations (Section 9.9).

#### **9.2 Reflection upon interpretive reflection**

The reason for undertaking this research was to come to know about the experience of living with comorbidity and the experience of a new diagnosis. In addition to this, a further objective was to appreciate the experience and interpretation people have of complex illness.

The context of cardiovascular disease and prediabetes was also of interest because this pathophysiological pattern of comorbidity had been observed in my own clinical work. To be able to coalesce all these facets in to one methodological option would have been awkward had a traditional qualitative approach been attempted. A methodology was sought which would allow some freedom to import methods and methodological strengths from other disciplines without incurring criticism that it did not theoretically suit clinical research. Interpretive description was selected for this research because it had been developed by the nursing discipline specifically with clinically based research in mind.

Thorne's (2008) book detailing interpretive description had just been published during the time I was finalising my research methodology. Thorne's book "Interpretive description" significantly supplemented the earlier papers that she and her colleagues had published to whet the appetite of nurse researchers seeking methodological rescue, as I did, from traditional theoretical approaches that did not methodologically assist in answering nurses' clinical questions. The immediate appeal of interpretive description was that it was designed to allow researchers to make methodological decisions and include substantive strands on the proviso that all decisions be logically reasoned and justified.

The research product should meet the evaluation criteria that Thorne (2008) developed in terms of epistemological integrity, representative credibility, analytic logic and interpretive authority. Table 9.1 (on page 161) shows how Thorne's (2008) evaluation criteria were addressed in this research. Detail describing the evaluation criteria are found in section 4.5 of this thesis.

A further point adding to the justification for using interpretive description in my research is that this methodology has now been widely accepted and used as a platform to analytically direct a variety of research in the nursing academe (O'Flynn-Magee, 2002) and research outside of nursing (Burns, 2009; Hunt, 2009), further examples are found in Section 4.3.3.5.

Three concepts became increasingly evident as the research progressed. They were risk (Section 9.5), self-care (Section 9.6) and complex illness (Section 9.7). This discussion aims to clarify how the concepts risk and self-care fit with a third concept, that of complex illness. The conspicuous and less conspicuous detail of risk and self-care are expressed separately but as the discussion progresses it becomes clearer how the juncture of these concepts are important to understanding the experience of illness as 'the whole', as complex illness.

**Table 9.1 Thorne's\* evaluation criteria**

<b>Evaluation criteria</b>	<b>Doctoral study</b>
<b>Epistemological integrity</b>	That knowledge is constructed; see Sections 3.4, 3.5, 3.5.1 of this thesis for epistemological position and justification.
<b>Representative credibility</b>	Sampling was according to availability of participants, participant group (n=33) has mainly been interviewed on two occasions over a nine month period.
<b>Analytic logic</b>	Evidence of inductive reasoning process: see methods chapter 5 section 5.5 onward and findings in chapter 6. Clear documentation of research process throughout thesis. Use of interview excerpts to support findings allows the reader to see the data behind the researcher's interpretation. Further interview excerpts are indicated (but not presented) to alert the reader of further excerpts not included in the thesis text.
<b>Interpretive authority</b>	Verification of interpretation with supervisors, see section 5.6.1. Verification also by reading broadly, outside the nursing literature. Statement by researcher of their theoretical orientation underpinning the research and it's congruence with interpretive description, see section 4.3. Use of interview excerpts to support researcher's interpretation again allows the reader to see the data behind the interpretation.

\*From: Thorne, S. (2008). *Interpretive description*. Walnut Creek, C.A.: Left Coast.

### 9.3 Outline of findings

An extended summary table (Table 9.2) displays the final thematic framework with all themes inclusive of embedded subthemes. All themes are related to the overarching theme inconspicuous and conspicuous detail. The major themes and subthemes represent the variety and depth of information that participants expressed during interviews. The embedded subthemes were an important extension of the framework; they surfaced while being open to, rereading and considering the interpretations that had already emerged in Chapters 7 and 8.

**Table 9.2 Summary extending thematic framework (Table 6.1) with additional embedded themes**

<b>Over-arching theme</b>	<b>In/conspicuous detail</b>					
<b>Major themes</b>	<b>Invisible disequilibrium</b>			<b>Dialogue as caring</b>		
<b>Sub-themes</b>	<b>Losing equilibrium</b>	<b>Becoming embattled</b>	<b>Evolving illness</b>	<b>Restorative dialogue</b>	<b>Caring</b>	<b>(Re)-constructing illness</b>
<b>Embedded subthemes</b>	(No new embedded subthemes)	Humour alleviating embattlement  Contemplating surgery  Delaying seeking advice	Perceptions of social constructions  Reliving a disarray of events  Experience of the living body  Pain and the living body  Illness evolves by remaking life	Dialogue for sharing burden  Medicalisation of detail	Life routines  Conspicuous medications  Conspicuous risk  Information  Caring for self	New constructions of illness  Perceiving well-being  Constructing complex illness

#### **9.4 Summary of findings**

Before reaching hospital many participants were unable to call for emergency services, this task was left to family, significant others, even calling friends who would then call emergency services (Section 7.2.1). Participants gave many reasons why they delayed seeking advice about the invisible disequilibrium they experienced (Section 7.2.2.3), this was manifest by a lack of confidence in understanding their new experiences of the living body. Participants described their evolving illness. For example in their interviews they were relieved to get to hospital when they had their initial acute event “. . . the anxiety level drops considerably the moment you step in the door” (CRW7, int1, p.3) as reliving a disarray of events. Most participants had experienced physical changes pre-hospitalisation but had not established their cause, for example “. . . the last two times I’ve used it [GTN] it’s given me a really bad headache which it never used to do so something has changed there” (CRW7, int1, p.3). Others lost equilibrium quickly and were urgently sent to hospital by phoning emergency services themselves or by other people. Participants experienced becoming embattled, a chaotic period when equilibrium

was difficult to establish or preserve. This pattern of patients providing a historical context is also noted in the literature (Gassner et al., 2002). The visible is extraordinarily vivid, and usually involving concurrent pain or another experience of the living body. As illness evolved participants reflected on the experiences of the living body and what these experiences could mean; their reflections became part of remaking a life (Charmaz, 1991).

Participants understood their cardiac status, for some, realising that their status was not curable: “if there is damage to the heart I would imagine that damage will just kind of be there, it’s probably going to have to [be] managed . . .” (CRW7, int1, p.10). This point of palliative care is also found in the literature, that life is finite for those with CVD (Nordgren et al., 2007). Participants were able to make the link between their family history of cardiovascular disease and diabetes to their own condition, although participants required these linkages to be made overt in our dialogue. Linking family history of CVD to living with experiences of CVD are also well reported in the literature (Gassner et al., 2002; Nordgren et al., 2007), however the literature does not extend this to the comorbidity of CVD and prediabetes.

Participants had various perceptions of psychosocial constructions of health and illness (Section 7.2.3.1), matching those presented in the literature (Bendelow, 2009; Blaxter, 2010). People’s constructions of illness are personal; health professionals can but support this process of (re)construction (Furze, 2008), to ensure a focus on long-term health rather than just acute illness (Blaxter, 2010).

The restorative dialogue (Section 8.2.1) reflected how participants talked with others (often a health professional) and gained some motivation to plan and execute self-care. Participants explained how they shared the burden of their illness (Section 8.2.1.1) by talking with others. The act of another listening was often reassuring to them. The restorative dialogue is akin to what Charmaz (1991) describes as protective disclosing or spontaneous disclosing. She describes protective disclosing as a means of controlled dialogue about aspects of illness by the patient, while spontaneous disclosing involves unprompted and perhaps even impulsive dialogue. During the interviews of this research it is evident that both forms of disclosure were encountered and that information is exchanged (Furze, 2008).

Participants had considerable focus on the medicalised aspects of their care (Section 8.2.1.2) which concurred with research exploring the experience of CVD (Condon & McCarthy, 2006). One developing issue was how and why people with illness access health information currently termed health information-seeking behaviour (Lambert & Loiselle, 2007). Participants relied heavily on their general practitioners for information and answering questions about their

complex illness (Section 8.2.2.4), behaviours all in keeping with the concept analysis developed by Lambert and Loisel (2007). There was less reliance on practice nurses, although this was likely to be practice-dependent and nurse-specific, for example information coming “from the nurse at the doctor’s surgery [about diabetes]” (CIM6, int2, p.6) for one participant. There were two participants who had negative relationships with their general practitioners. During interview 2, one participant explained that he would find it difficult to find a new doctor because the area that he lived in was short on medical coverage, he believed it was better to have a doctor that he did not completely trust than no doctor at all (CSC8, int2). Across Chapters 7 and 8, participants wanted to be able to communicate well with someone who was a reliable source of information regarding matters of health and illness, as one participant said “. . . books and internet have no empathy” (CRW7, int2, p.24). The above points as findings are indicative of a need for excellent communication between patients and health professionals. This is not a new issue, communication being primary in order for patient together with health professional to deal with and adapt to living with complex illness (Furze, 2008). Patricia Manhire (2011) skilfully explains what the participants of this study allude to, a nurse to assist the patient through the complexities of self-management and self-care for those with illness.

Life routines were discussed extensively by participants especially eating and alterations in diet, losing weight, plus staying active (Section 8.2.2.1). The addition of medications to life routines was inescapable (Section 8.2.2.2), a few participants openly stated they would rather not be on medications (Section 8.2.2.3). Some participants did not wish to give up some of their life routines such as smoking or alcohol use (Section 8.2.2.3). Participants made efforts to refrain from life routines that incurred risk to health in order to avoid further cardiac events or progression to a diagnosis of diabetes. Participants described a range of self-care activities to avoid progression of ill health (Section 8.2.3). These aspects of caring are in agreement with current research (Madjar & Walton, 1999; Malpass et al., 2009), with particular emphasis on patients making decisions about their own life routine.

Three pivotal concepts are identified from the research: risk, self-care and complex illness. These concepts are synthesised to highlight the interplay between them as important concepts to consider in clinical settings. The examination of risk, self-care and complex illness is supported by the literature to demonstrate the current landscape of thought.

## 9.5 Risk in the construction of illness

Risk pertaining to living with illness is a major finding for this research; it was repeatedly evident in the dialogue with participants and therefore warranted establishing as an embedded subtheme. Risk was inconspicuous at times, catching participants unaware of the risk they had taken with their health. Alternately, risk became conspicuous as, for example, some participants had pain in their chest, that some chose to dismiss. Risk was also a conspicuous detail, risks were taken when ignoring signals from the living body that their equilibrium was awry.

In the context of this research, risk is identified as a sociocultural and historical construction (Blaxter, 2010), in which participants had located themselves as individuals with illness. As individuals, the participants did not tend to talk about risk directly, it was more evasive, they shrugged shoulders, and they looked down at the floor when they explained they had not done enough to reduce their weight, or eat a diet considered healthy. Some participants ignored risk “we can’t last” (CRW7, int1, p.5), expressing their resignation that risk and its eventual outcome was inevitable.

The participant’s view of risk and how this may affect their health was a unique personal view as it pertained to their construction of illness. In view of this, participants did not take risks, they made choices. Some participants did not continue a healthy diet or even over dieted, this was their choice, part of their continuing sociocultural construction of a personal understanding of illness. As an interpreter, this meant appreciating that people took risks that may affect their health, this in turn being my interpretation of their choice. Risk is aligned with choice (Douglas, 1992; Lupton, 1999) and preference, which in turn is inextricably linked to socioculturally learned assumptions (Douglas, 1992).

Lupton (1999) describes six classifications of risk: environmental (e.g. pollution, radiation), lifestyle (e.g. diet, use of drugs, alcohol consumption), medical care (medicalisation), interpersonal (social relationships, power), economic risk (e.g. unemployment, socio-political manipulation, globalisation) and criminal risk. The participants involved in this study covered all six classifications in their discussions about their experiences of illness to some degree. As an example participant 9 in Section 8.2.2 described how his life routines at that time were likely to have a negative effect on his health. What he described were his personal choices, a reflection of his culture, as opposed to socially or medically imposed constructions of risk (Godin, 2006).

Lupton’s slicing up of the concept of risk into 6 categories requires reassembling back into personal constructions of illness to affirm their interconnection. Understanding how Lupton’s

categorisation of risk intersects with patients' personal constructions of illness would be clinically of value as this may focus both patient and nurse on which risk/choice is hazardous to personal health. For example one participant was using a recreational drug (conversation off tape), although a personal choice, was likely to have contributed to his unexpected myocardial infarction. Application of Lupton's classification to this personal choice may be categorised at several levels in terms of risk: lifestyle (use of drugs, alcohol consumption), interpersonal relationships with family and colleagues, economic risk and criminal risk. The conversation with the participant was not directly about risk; the conversation was concerned with making overt his personal choice, and assisting in understanding how choice augmented the complexity of his illness.

The participants of this study referred to risks taken in the course of their life; what they did that potentially increased health risk (e.g. high fat diet, over eating, eating the wrong types of food, not exercising, and participating in sedentary lifestyles). Participants also talked about how they tried to avoid risk by explaining what they did in terms of improving their diet and becoming more active. Participants made attempts to avoid risk as long as it did not interfere with sociocultural mores (Lupton, 1999).

In this research, risk was a construct determined in part by the sociocultural contexts that participants lived their lives in. Risk is well represented in the health, sociological and medical literature. A variety of positions are addressed: embodied risk (Robertson, 2000), risky self (Ogden, 1995), sociopolitical context (Lupton, 1999; Lupton & Tulloch, 2002), broad nursing context (Fanany, 2012; Liamputtong, et al., 2012), epidemiological context (see section 1.3.2 of this thesis), modifiable risk factors (Wagner, Lacey, Abbott, de Groot, & Chyun, 2006), patients perception of required lifestyle changes (Wiles, 1998), screening in terms of public health (Hann & Peckham, 2010), no-risk behaviour (Douché, 2007), discourse of risk and prophylaxis (Douché & Carryer, 2011), and risk as a construct (Robertson, 2001).

A further perspective of risk relevant to this research is the modifiable risk factor. This doctoral research found participants spoke about modifiable risk factors that contributed to their construction of complex illness rather than their construction of health. In section 8.2.2.3 participants 10, 9 and 15 talked about risk factors they chose to modify, and mainly intended to change their behaviour to ensure adjustment or avoidance of risk. The medical concept of screening for modifiable risk factors as pathophysiological phenomena, is also found in the literature in terms of screening for health risk (Heyman, 2010; Robertson, 2001) or surveillance of risk factors (Godin, 2006).

Interpretive research addressing familial hypercholesterolaemia from a medical perspective concludes that patients with a family history of high blood cholesterol construct their understanding of their condition from a genetic and familial perspective (Frich, Ose, Malterud, & Fugelli, 2006). Participants in this study with a family history of cardiovascular disease were aware of their family history as contributory to their illness. Participant 21 has a family history of CVD (see end of Section 7.2.1 for detail). Participant 21 immediately communicated with his brother who in turn had his cardiac risk assessed (an angiogram revealed less CVD than his brother, participant 21). Participant 21 also drastically altered his diet and physical routine to reduce his risk of progressive CVD. This participant's reaction to his ill health demonstrated how people's thinking about risk and understanding about risk was not only from a genetic/familial perspective (as influenced by medicalisation), but also socially constructed within the cultures we participate in (Douglas, 1966).

There is a growing exchange of ideas concerning the overlap of the person with chronic disease, the experience of this condition and the provision of reducing risk (Aronowitz, 2009). This gives rise to what Aronowitz describes as a convergence of the experience of risk and chronic disease. This is an interesting point to consider, referring to preventing risk in those already beset with chronic pathology and illness. Evidence of this experience is peppered throughout this research, participants came to hospital with an acute coronary syndrome event, were found to have high blood glucose and immediately subjected to a further battery of testing to confirm medical diagnoses but also 'checked' for other risk such as diabetes, hypertension, hyperthyroidism and so forth. It is important to reduce the burden of chronic disease but in terms of well-being perhaps choices should be offered to the recipient of this surveillance. Participant 3 in interview 1 briefly mentioned how he declined angiography some years ago, this participant died before he could be interviewed a second time. If he had had angiography sooner would he have lived longer? It is possible the participant chose well-being over attending to physical risk, turning inward to make sense of risk as a danger to health (Beck, 1992; Lupton & Tulloch, 2002), rather than be subjected to "the politics of risk distribution" (Aronowitz, 2009, p. 420).

In this study, participants perceived risk within their sociocultural context, which in turn contributed to their own perceptions and understanding as a construction of risk (Douglas, 1992). In turn, the participant's construction of risk variously affected their construction of health or illness. Participants explained that they made choices about conspicuous detail, rather than opting for modification of risk factors as a medical construct. The dated medicalised option of educating patients in terms of modifiable risk factors is precisely what several participants chose not to take note of. This is not because they are reckless, more that participants are people

making choices according to their sociocultural framework that structures ‘the whole’ of their lives. Keystone to health professionals working with people is to become sensitive to patients’ sociocultural constructions of risk, listening to what they identify as their choice.

## **9.6 Self-care in the construction of illness**

In this section the aim is to explore how self-care became an important component in participants’ constructions of illness. Participants engaged in a dialogue as caring (major theme) while recovering from an acute coronary syndrome event. The dialogue of self-care is focussed on notions that both the participant introduced into the conversation and direct questions the researcher asked. The focus of self-care is on detail that is conspicuous or becoming conspicuous. The dialogue is about “being ready for and open to everything” (Gadamer, 1993/1996, p. 73), being ready for “the visible [as] a landscape, a topography yet to be explored . . .” (Merleau-Ponty, 1964/1968, p. xlvi). Once participants were told about particular conditions (CVD and prediabetes), the dialogue as caring commenced as a restorative dialogue, caring for self and/or (re)constructing illness.

The terms self-care and self-management are often used interchangeably (Kralik, 2010; Kralik, Price, & Telford, 2010), when conceptually they differ (Paterson, Russell, & Thorne, 2001). A reliable way to separate out these concepts is offered by Kralik Price and Telford: “self-management education plays an important role to understand the biomedical construction and consequences of the disease process, self-care involves a dynamic, experiential process of learning, trialling and exploring the boundaries created by illness” (2010, p. 200). The definition offered by Kralik et al. summarises and concurs with the findings of this doctoral research, that self-care is an attitude to consciousness, with “a sense of ‘being’ and ‘becoming’” (Kralik, et al., 2010, p. 200). In Section 8.2.2.5 participants in this research were becoming informed, more confident about their living body and thus making decisions about care.

Participants were the chief decision makers about factors imposed upon their health or body (see Section 8.2.2.4). This is in agreement with previous research showing people with illness were their own principal caregivers and as a caregiver they made their own decisions (Kralik, et al., 2010). Self-care was a dynamic process of decision-making for the participants, an ever evolving construct, again in agreement with the literature (Kralik, et al., 2010; Paterson, et al., 2001).

Integral to self-care is the notion of patient independence with support available from health professionals. Supporting patients in their self-care decisions is in keeping with the concept of dialogue and caring attentiveness by health professionals (Jonsdottir, et al., 2004). It identifies the participant as chief caregiver of him/herself (Kralik, et al., 2010) but recognises a level of attentiveness from the supporting health professional. A New Zealand example can be called upon here. In 2010, the New Zealand Guidelines Group reviewed research for effective health behaviour change interventions for people with chronic illness (New Zealand Guidelines Group, 2011). Associated with this was a case study of care for those with cardiovascular disease. The Heart Guide Aotearoa programme was successful, one reason being that the programme was patient-centric (Henwood & Moewaka Barnes, 2008). A similar view is taken by Jonsdottir et al. (2004), that nurses in partnership with patients are “in an open caring attentiveness to whatever emerges in their dialogue” (Jonsdottir, et al., 2004, p. 242). Partnership is a balanced patient-centric relationship, which aligns with the major theme dialogue as caring from this research. Similarly the theme caring relates to the equally balanced working relationship that patients and health professionals ideally should engage in.

Self-care is also concerned with access to support from health services, including support from health professionals and products (Noyce, 2011). The participants in this study offered comprehensive information about support services they used and how successful they were. For example, participants partook in a cardiac rehabilitation programme with positive comments about its worth. A common remark made was a need for ongoing support such as that offered by cardiac programmes, which people could self-access for ongoing motivation and information. This finding indicates that services are not providing what patients identify as their need(s). Prior research also highlights this, but further clarity is required to appreciate patient agendas in self-care support and self-management (Kennedy, Gask, & Rogers, 2005). To understand the patient agenda requires working with patients beyond managing signs and symptoms and treatments, includes working with psychosocial concerns and lifestyle changes (Barlow, 2010). A solution is to focus upon patient-centric relationships, hold dialogue, wherein self-care support is an accepted aspect of health service provision (Litchfield & Jonsdottir, 2008; Manhire, 2011).

There is a link between risk in illness and self-care for illness. In sections 8.2.2, 8.2.2.1, 8.2.2.2 there are many examples of mixing risk with self-care. For example in section 8.2.2.2 conspicuous medications, participant 13 reasoned that he may have chest pain because his regular medication, diltiazem, was inadvertently not prescribed. He interpreted that he was at risk of experiencing further angina; he was caring for himself by chasing up his general practitioner to arrange corrected prescriptions. He further tried to reduce risk (or make choices)

by suggesting he “might bring it up with [cardiologist], I get more out of him than with the GP”. Self-care is *apropos* of learning about ‘the whole’, avoiding and pre-empting risk, finding solutions to problems that health professionals cannot be aware of in the day to day events of a person living with complex illness. This processing also described in the literature (Paterson, et al., 2002) with regard to information exchange between patient and health professionals, constructing healthy life routines, and the temporality of disease-specific features.

Health behaviour (Alonzo, 1993), as are personality and sociocultural development of the individual (Blaxter, 2010), are further facets relating self-care to risk. These facets shape what one does to either avoid risk (proactive self-care), or what one does to treat disease because risk has been ignored (reactive self-care) (Ziguras, 2004). In Section 8.2.2.4 participant 4 discussed the reactive use of GTN spray to instigate self-care for his chest pain. With time he may also learn about the proactive use of GTN spray to maximise self-care. Incidents such as this confirm how participants reallocated risk, or made reasoned decisions, by becoming proactive in self-care as part of their continuing experience of complex illness.

## **9.7 Complex illness as experience of ‘the whole’**

“We must understand the whole in terms of the detail and the detail in terms of the whole” (Gadamer, 1960/1998, p. 291), provides a good reflection upon the aims of nursing as an art as well as a science. This effectively requires working with patients to revitalise humanness in nursing (Jonsdottir, et al., 2004), beyond medicalised illness and implications of comorbidity and politicised health care. The findings of this study are in agreement with other research about prediabetes (Andersson, Ekman, Linblad & Friberg, 2008), that health professionals be guided by patients’ understanding of their situation, that dialogue include patient experience and their perspectival questioning.

Participants in this study demonstrated how they were not ready for ‘the whole’. They were frequently focussed on one problem at a time while in hospital, they seem to be physically stressed and/or exhausted not allowing them to efficiently assimilate multiple problems regarding their health or complex illness. The participants disclosed how they reflected more upon their care as they recovered. The ability to reflect was notable for those people who were interviewed for interview 1 in the community (rather than in hospital), and later for most participants interviewed for a second time (see end of Section 7.2.3.1 for similar confirmation). Even those who had undergone substantial surgery or had had large myocardial infarctions were more reflective during their first interviews at home (rather than in hospital) i.e. they were

thinking purposefully; they asked questions to help them make sense of their experiences to make sense of “a giant mess” (Dennis, Larkin, & Derbyshire, 2013). The participants also tried to make sense of inconspicuous detail such as prediabetes, described as ambiguity by Dennis et al. (2013). Through this accumulated understanding participants gained a “profound respect for the complexity of the challenge” (Thorne, 2008, p. 84), participants began to reconstruct an insightful interpretation of complex illness.

This research aimed to distinguish how participants were descriptive and reflective (evolving illness) or how participants gained understanding and interpreted their experiences ((re)constructing illness). The findings of this research made some distinction; in section 7.2.3 the excerpts are reflective whereas section 8.2.3 provides examples of participants who have begun to interpret their experiences, formulated meaning to comprehend how complex illness fits with ‘the whole’.

Participants gained insights about their condition from self-awareness and reflection upon the events that transpired. To reiterate a point made by Gadamer “It is only through a disturbance of the whole that a genuine consciousness of the problem and a genuine concentration of thought upon it can arise” (Gadamer, 1993/1996, p. 73). Through self-awareness one comes to know about a personal understanding of illness or health. Participants were reflective in the interviews, some more than others. In this reflective mode participants explained they had to ‘cut and paste’ new *modus operandi* into their lives; new life routines, appointments, medications, communicating with all manner of health professional. How this was conveyed, was at times, a jumbled conversation that at times lifted at the end with an explanation. Gadamer writes: “This incapacity for completeness has a positive side: it reveals true infinity of the mind, which constantly surpasses itself in a new mental process and in doing so also finds the freedom for constantly new projects” (1960/1998, p. 426). For example participant 33 (Section 8.2.2.4) related a long explanation in our interview, of how he knew his own body as he had just been telling the story of nurses trying (unsuccessfully) to insert an intravenous cannula. At the end he exclaimed: “the patients do know some things and we know our own bodies and we know what’s happening with our own bodies you know” (CWA33, int2, p.4). Participant 33 explained that he knew his body and was frustrated that health professionals did not acknowledge this. The incompleteness of his initial conversation leading into “we know our own bodies” is punctuated with incomplete thought and speech “No I don’t think I . . . , when I was in with the heart attack no I don’t think. . .” (CWA33, int2, p.4). Participant 33 provides insight into the true infinity of the mind (Gadamer, 1960/1998) thinking out loud, formulating ideas, an ongoing effort of reshaping his construction of complex illness.

This study shows how living with new and old aspects of illness requires making many decisions about how one lives one's life. How health professionals provide care to support people in their choices and decision-making is often influenced by biological data and science. The support offered should be enhanced by supporting patient goals and patient-identified needs, and providing humanness in health care delivery.

## **9.8 Implications for nurses working with people with complex illness**

Cardiovascular disease and diabetes are both on the rise in New Zealand and internationally. The research presented in this thesis explores the experience people had of cardiovascular disease and prediabetes, and how they came to interpret their experiences. This study looked at the convergence of initial CVD and the secondary diagnosis of high blood glucose putting people at potential risk of developing type 2 diabetes. This is the opposite to how reviews are constructed, with emphasis on patients with diabetes and then prospective advent of cardiovascular risk (Gakidou, et al., 2011). In clinical settings it is noticeable that patients present with increasing comorbidity especially those people that are older (Minnee & Wilkinson, 2011; Williams & Botti, 2002), hence all permutations of comorbidity could be considered for research.

This research highlights issues significant to those people living with complex illness as opposed to those people with a singular chronic condition. There has been prodigious research over the last thirty years revealing the experiences of people living with illness as a singular diagnosis as reviewed in Chapter 2. Perhaps inadvertently researchers have focussed on diagnosis, rather than people with illness, regardless of the extent of comorbidity, inclusive of all the elements of life and living involved in such a case.

Recommendations for nursing practice and research that emerged from this research are presented in the following section, to support people with complex illness.

### **9.8.1 Recommendations for nursing practice and research**

The following recommendations are made:

1. The theoretical framework developed from this research provides a unique process to identify patient's status as embattled or in restorative dialogue in terms of experiencing illness. Four recommendations (with detail) are made:

- a. Recommend that the overarching theme, in/conspicuous detail, be used as a guide to clinicians to reveal the patient interpretation of their experience of complex illness.
  - b. Recommend establishing if patients are embattled and/or open to commencing or maintaining a restorative dialogue about their well-being and complex illness. The findings of this study show how patients become more open to the complexity of their illness over the passage of time.
  
2. People with complex illness are constantly seeking health information and avenues to update and verify information to support self-care.
  - a. Recommend that nurses engage in ongoing restorative dialogue to identify patients' ongoing health information needs as part of ongoing self-care.
  - b. Recommend that multi-modal forms of information (e.g. verbal, printed and electronic) are available to patients as the findings in this study find that multiple modes of information were accessed.
  - c. Repetition of information is likely to be needed and should be offered to patients with complex illness.
  
3. Recommend that nurses working in any clinical setting listen to patients, hear what the patient identifies as their needs, not what nurses or other health professionals believe the patient's needs are.
  - a. Recommend the theoretical framework identified in this research provides a frame for clinicians to address patient needs by being self-aware and actively hearing what patients are telling them.
  - b. Recommend that active listening is reinforced in nursing education as an important tool across all clinical settings for clinical reasoning; to actively hear what patients are telling clinicians their needs are, not what the clinician believes their needs should be.
  
4. Recommend the use of interpretive description in future clinical research. It provides a set of guidelines that can be adapted to the unique nature and purpose of the clinical research at hand.

The above recommendations have evolved from both undertaking this research and from the identified research findings. Added to this, all of the recommendations are relevant to nursing education. The recommendations support the need for nursing education to inspire students of nursing to become active listeners and work with the patient and their families, to identify their

needs and realistic goals or outcomes. A specific recommendation has been identified to address how this research contributes to nursing education (Recommendation 3b). Further to this, from my own experiences as a researcher, I would encourage all students of nursing to identify their own bias and culture so they may become more self-aware and culturally aware of how this bias impacts upon their role as a nurse.

Participants focussed on their cardiac condition while in hospital, interview 1 indicated this. There was little energy to absorb or look outside of their cardiac status. In interview 2 participants discussed a range of issues which for some included a dialogue about their high blood glucose and cardiac status (see Section 9.5.2.1). The discrepancy found in energy levels and readiness to enter a restorative dialogue by participants is an important finding in support of recommendation three above. This indicates that the nature of care is always work in progress, according to the level of engagement in restorative dialogue between patient and nurse.

An example of how the recommendations relate to clinical nursing is offered. The WHO 2008-2013 action plan for the global strategy for the prevention and control of noncommunicable diseases is aimed mainly at CVD, diabetes, respiratory diseases and cancer. In New Zealand, the new Health Promotion Agency (HPA) as of November 2012, has outputs related to nutrition and physical activity which in turn relate to reducing obesity, in turn linked to risk for chronic illness such as type 2 diabetes and CVD (Health Promotion Agency, 2012). The new HPA statement of intent does not specifically target noncommunicable diseases, as the WHO does. However, there are efforts made to update assessment in the New Zealand Guidelines Group "Primary Health Care Handbook 2012" (New Zealand Guidelines Group, 2012), recommending the combination of cardiovascular risk assessment and screening for diabetes. This too relates to the research recommendations; listening to patients is core business for those nurses working in roles both in hospitals and community settings assessing for risk of CVD and diabetes. Nurses are present as a resource, as an interpreter of new body cues, and as self-care support (Carryer, et al., 2010; Thorne & Patterson, 2001; Thorne, et al., 2003).

## **9.9 Other possible themes and concepts relevant to this research**

In terms of clinical relevance there are further themes that arise from the interview data beyond the reported data analysis and synthesis of this thesis. Chapters 6, 7 and 8 focussed on themes and concepts that were immediately evident from the interview data. The themes shaped the theoretical framework, the framework in turn supporting three principal concepts (risk, self-care and complex illness) which are presented in this discussion chapter. Other potential themes and

concepts relating to this research that could be synthesised further are: experience of the living body, fear of dying and health within illness.

The subtheme experience of the living body permeates in/conspicuous detail, as details are experienced through and of the living body. The experience of the living body was revealed while losing equilibrium (Section 7.2.1) as participant 7 explained:

I'm permanently tired, no energy, sleep badly . . . feel bad; just don't feel well most of the time.(CRW7, int1, p.1)

As the invisible disequilibrium took hold participants expressed their living body:

It was a feeling – wouldn't even call it pressure at that stage. It was like something moving up my body, and it wasn't painful. (CGB22, int1, p2)

I started feeling a little bit dizzy, nausea. (CAH25, int1, p.2)

I had some chest pains, cold sweat, pins and needles in both of my arms and upper chest, which lasted for about 10 – 15 minutes. (CRY30, int1, p.1)

The participants talked about their body and how it altered as equilibrium was lost and as they became more embattled (Section 7.2.2). As participants became embattled the experience of the living body turned to the potential of a dying body:

I knew I was dying, or it felt that way. (CPC2, int1, p.3)

This brief quote highlights another theme, that of fear of dying. Fear of dying too warrants further examination but was not explored as a major part of this thesis. Some participants dwelled upon dying:

I don't care about dying. That doesn't worry me. But I do want to be able to live. There's no point in being on this earth if you can't live. (CDM10,int1, p.7)

Participant 10 above melded together the experience of dying and living. That dying was an experience she was not concerned about, but while she was alive, while she experienced the living body there was a desire to live well. Tying together the experiences of the living body and the dying body would be an important notion to explore further.

The concept health within illness (Carel, 2008) is yet another angle of interpretation that may have been taken for this thesis. Potentially this concept has a lot to offer in terms of understanding complex illness from the patient's perspective as older nursing research demonstrates (Moch, 1989). Participants expressed negative effects from their experiences of illness:

I don't feel strong enough to do the things that I want to do. I just feel that it's interesting that my body's let me down - or I'm frightened of pushing myself to do

more. . . I don't trust my body any more to be strong enough to do what I want to do, which is frustrating for me. (CJG16, int2, p.1)

Participant 16 described how her living body failed her, she had lost confidence, and her experiences began to show how illness-orientated her life had become. In her interview she dwelled on her depression that had developed since her myocardial infarction, and that she was attending counselling to improve her health. There was little health within illness noted in this particular interview by the participant, details of health were inconspicuous.

The following participant explained how his experience of an ACS event had a silver lining:

The main thing was giving up smoking that was you know like at the end of the day I lay a lot of fault at the door of smoking . . . then regular health checks obviously going in and get my bloods done like three monthly routine with my doctor and then we go through the results. [The doctor is] a hard person to get time with so doing that regularly getting into that slot has been good. (CRS34, int2, p.14)

After his myocardial infarction participant 34 found his experience prompted him to develop a regular routine to visit his doctor and give up smoking. The experience of illness galvanised some participants like participant 34 to find health from their brush with ill-health.

Other participants had comparable experiences but involved preserving a level of health within a continuing experience of illness:

I've got a very good friend. She lives two houses down and we played croquet together . . . when I was sick she rang me up and said is there anything she can do. So, I said well I've got to go to the doctor tomorrow. Oh, she said, I'll take you. I said, but it's your mah-jong day. No, she said, it doesn't matter – I'll come and get you. So, she took me. Then, twice she rang and said she was going to the shop – did I want anything? I think once she got me something, but she always says now, if anything goes wrong, give me a ring – I'll come straight away – and she would. (CIM6, int2, p.15)

The above quote is from a participant who lived in an aged care facility. She explained how she was still able to maintain her independence, but through the experience of illness had developed a friendship with a neighbouring resident. This friendship had been accelerated as a result of participant 6's illness and has become a healthy relationship of independence with the mutual understanding that help is only a phone call away. In view of this, (mental) health within illness was evident as participant 6 recognised the ability to maintain her independence and yet had peace-of-mind knowing that her friend, a few doors away, was available should her health deteriorate. The concept health within illness helps begin to demonstrate how there is a grey area between the two entities of health and illness. Participant 6 above shows how illness and health coexist, not as separate states, not as a binary form.

These themes are worth considering for separate publication or future research, as they reveal further important patient perspectives of complex illness. Understanding the experience of the living body, fear of dying, and health within illness are conceptually just as important as risk and self-care as they all contribute to the greater understanding of ‘the whole’. The concept health within illness has limited current nursing research; a concept analysis or new dedicated research is needed to truly reveal its value.

### **9.10 Limitations of the research**

A major limitation of this research concerns itself with accessing the subjective human experience. Interpretive description methodologically attends to illuminating the human experience in clinical settings which can be notoriously difficult to access. As this experience is subjective and often subtle “products are not inevitably accurate, relevant, or even necessarily socially responsible, and the knowledge deriving from them will be no more or less credible than knowledge derived from a range of alternative sources” (Thorne, 2008, p. 221). With Thorne’s caveat in mind credibility of the subjective experience is attended to in this research by referring to the theoretical perspective throughout the research process and the research findings presented in this thesis. It is not that the findings are presented in an interpretive descriptive manner; it is more that they are presented in such a way that stays true to the theoretical perspective both ontologically and epistemologically, and the document is written in such a way that there is clear analytical logic defining the research methods and how inductive reasoning occurred. As an example, the researcher acknowledges there will have been incidents wherein the researcher inadvertently led conversations with participants. Interpretive description as a methodology gave the researcher ontological freedom to admit to these incidents and an opportunity to work through reflective correction. The openness of working with the subjective experience by instigating interpretive description nullifies the concern of this particular research limitation.

The first interview was undertaken either in hospital immediately after admission or within two weeks of discharge home. Appendix 6 presents a summary of the two locations and times of the first interview. About a third of participants were first interviewed after they had been discharged home. The timing of interview 1 was crucial which became clear once interviewing had commenced. Timing of interviews presented a potential bias of subject matter or experiences raised by participants.

An additional noticeable issue around interviewing patients in hospital was that they were often physically exhausted and sleep deprived. This was noted in the reflective account on a number of occasions after an interview was completed. Immediately after interview 1, the participants' appearance, the environment, their emotion and cognition were noted, hence the bias also came to light. From the AEEC Table (see Section 5.4.2.1) and reflective notes participants interviewed in hospital were tired but enthusiastic about their involvement in the research.

A further research limitation worth mentioning was the challenge of finding a suitable interviewing environment for interview 1 (refer to Section 5.4.3) for those hospitalised. Participants interviewed in the hospital environment had less privacy to speak their mind, therefore participants were given the option to be shifted to an interview room as able. Sometimes shifting was not an option, particularly if mobile telemetry<sup>18</sup> was not available.

Another factor which required consideration was how previous experience of hospitalisation for the same event would influence their experience and interpretation. Some participants had been in hospital before for a myocardial infarction, previous cardiac surgery such as CABG or interventions such as angioplasty. It was of interest to consider how dissimilar constructions of illness were between participants. Was there a difference for those participants for whom this was a new experience as compared to those who already had experienced a cardiac event and therefore some insight from previous experience? The difference noted was more the realisation that the variety of responses even in a group of 33 participants seemed extensive. All participants were developing their own construction of illness, hence experiential learning and interpretation was evidenced at an individual and personal level. At a theoretical or conceptual level, all participants' demonstrated similarities, accordingly the development of the thematic framework in my research.

## **9.10 Conclusion**

This research has shown how participants with complex illness led complex lives. A key finding is that participants acquired their perspective of risk according to learnt sociocultural and historical perspectives. A second key finding is that all participants engaged in some form of self-care and that nurses are in an excellent position to support patient's self-care by engaging in open communication and active listening. Patients should lead any clinical discussion of what their needs are as opposed to what nurses believe the patient's needs are. Final points discussed

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<sup>18</sup> A small mobile unit the patient is attached to, that sends ECG information to a central consol within the Cardiac Care Unit so ECG anomalies can be acted upon promptly. ECG data can be compiled and stored for the patient wearing the telemetry.

in this chapter are how the patient's perceptions of risk and self-care are central to constructions of complex illness.

The evaluation criteria developed by Thorne (2008) for qualitative research using interpretive description as methodology are examined. These criteria have been applied to this research, demonstrating epistemological integrity, representative credibility, analytic logic and interpretive authority.

The features that differentiate this research from other research are threefold. First there is concerted effort to work with the participants' interpretation expressed as a manifold mix of physical and psychosocial phenomena concerning complex illness. This in itself is not new but the attention to the experience (often descriptive) and interpretation participants placed on their experience is central to this research.

Another distinctive feature of this research is attention to the experience of a new medical diagnosis, acknowledging that this is a difficult and often frustrating and conflicted time for participants to incorporate the new experiences into their constructions of illness. A third novel attribute of this study is the focus of exploring the experience people have of comorbidity specifically the combination of cardiovascular disease and prediabetes, interpreted as 'the whole', or in this document referred to as complex illness. Collectively these three features mark out further knowledge essential to striving for excellence in clinical care of patients.

## **Chapter 10**

### **Conclusion**

#### **10.1 Introduction**

Complex illness was expressed by the participants of this research; their reflections of experiences of CVD and prediabetes bore testament to the labyrinthine nature of living with illness. It was crucial to hear and value the patient voice to gain deeper insight into patients' needs as individuals with complex illness. The theoretical perspective and methodology employed throughout my research ensured that the participants' perspective was key.

A concluding account of the research process is presented here with pivotal findings from the experience and interpretation revealed by participants. This chapter additionally offers suggestions for further possible thematic development, ideas for future research and a final conclusion.

#### **10.2 Returning to the research**

The research reported here is distinct in that it explored the experience and interpretation people had of an acute coronary syndrome event also found to have prediabetes. Additionally, the exploration disclosed how participants lived with comorbidity as complex illness. This research is unique because the research interconnects these three factors: the experience and interpretation participants express, specific to comorbidity, with focus on complex illness as per cardiovascular disease and prediabetes. Thirty three participants were interviewed twice, first in hospital (11 were interviewed at home immediately after discharge) and then approximately nine months later in the community. Two people withdrew from the research, and two others died before they could be interviewed a second time.

A thematic framework was developed to organise the data in to themes. The overarching theme is in/conspicuous detail indicating the visible and the invisible elements of complex illness. The first major theme invisible disequilibrium indicates the experience of illness and is supported by three subthemes: losing equilibrium, becoming embattled and making sense of evolving illness. The second major theme is dialogue as caring, more in keeping with interpretations of the

experiences that participants had. The three subthemes supporting dialogue as caring include: restorative dialogue, caring and (re)constructing illness.

Three main findings were revealed from this research. Primarily people living with an acute coronary event such as a myocardial infarction or unstable angina constructed or reconstructed understanding and interpretations as complex illness. Complex illness is the occurrence of an intricate meshing of signs, symptoms and circumstances, via collective experience, understanding and ultimately how people interpret their illness as both visible and invisible.

A second finding is the aspect of risk as choice as it relates to the construction of complex illness. In the context of this research, risk or choice was related to sociocultural and historical constructions of how people live their lives. The participants of this research took risks or made choices while they experienced complex illness, their behaviour relating to the social mores of groups that they participated in, for example their families or with friends. In making choices, participants discussed how medicalised modifiable risk factors effected their lives, greatest deliberation was placed on diet and routine activity.

A third chief finding is concerned with self-care as it relates to complex illness, and is indicative of the dynamic experiential process of learning and experiencing the limitations set by illness. Risk and self-care are conceptually linked, reactive self-care as risky choices potentially causing ill-health (e.g. smoking or taking a high fat diet), proactive self-care relating to health promotion or activities that attenuates complex illness. Participants recalled self-care as both reactive and proactive. Self-care was supported by a restorative dialogue for sharing burden and learning about medicalised detail. Self-care was also concerned with attending to conspicuous and less conspicuous detail working toward (re)constructing illness as complex illness.

Some participants struggled with complex illness conveying their extensive loss of equilibrium and expressed a magnified state of embattlement. Participants who were more successful at (re)constructing illness as complex illness strived to grasp 'the whole', this in turn appreciably improving their well-being. The research findings display a wide range of topics and conceptual features that arose from the rich dialogue with participants. For this reason consideration has been directed to how prospective research could be shaped.

### 10.3 Future research

This study recruited participants from a ward setting and accepted all those willing to participate. There was no targeted recruitment in terms of sex or ethnic group. The research sample had no participants from the Pacific Island people, but did have two Maori participants. As the prevalence of CVD, diabetes and prediabetes is significant amongst Maori and Pacific Island people (see Section 1.3.1), it would be important to undertake prospective research such as this research with these particular groups of people. A carefully developed culturally sensitive research process would permit people with complex illness to express clearly to health professionals what sort of support is required by people from a variety of ethnic groups.

This research is a precursor to further investigation that considers the many potential combinations of diagnoses that are found amongst people with complex illness. As an example this research has focussed on the combination of CVD and prediabetes; there is excellent local New Zealand evidence to suggest that this could in future be expanded to include CVD, diabetes and gout (Winnard, et al., 2013). Further consideration could be given to all manner of symptom combinations.

Participants in this research were embattled immediately after an acute coronary syndrome event, experiencing a cardiac diagnosis and making an effort to understand what this could mean. This was further complicated when a second diagnosis was announced (prediabetes). While hospitalised participants immediately began to come to terms with their illness, an understanding of their illness was evolving. However from observations recorded in the reflective account and from what participants said, participants were generally overwhelmed and needed time to absorb their circumstances. A future study to explore the experience and understanding people have of their complex illness would best include an interview at three time points. These time points would be: before discharge, three months after discharge home to ascertain how motivated participants remained and a third interview at twelve months. The third interview would aim to establish how participants had persevered with a restorative dialogue, health care and caring to improve or maintain health and well-being.

Further research may also include a follow-on study, re-interviewing participants from this research for a third time to ascertain how their construction of complex illness has altered if at all. As Gadamer explained understanding is always evolving, therefore participants' horizons will have altered significantly over time according to their experiences and experiential learning. A prospective study could have several foci. One focus could be on self-management and self-care, how people have worked with detail (conspicuous or otherwise) to care for

themselves. A second focus could be that of health beliefs, examining what people know about their health (Furze, et al., 2008; Furze, Roebuck, Bull, Lewin, & Thompson, 2002) and how this changes over time according to the extent of complex illness.

#### **10.4 Final conclusion**

Interpretive description offered an invaluable methodological approach to examine the experience and interpretations of people with complex illness, as CVD and prediabetes. The knowledge that has emerged values the knowledge of the participant-as-patient, adding to the patients' voice as they experience and interpret complex illness. This awareness aids health professionals such as nurses to come to know the participants' perspective, this being especially important if health professionals and patients are to work together successfully to better address patient needs. This research unmistakably supports the notion that nurses working in any clinical setting listen to patients, hear what the patient identifies as their needs, not what nurses believe the patient's needs are. To remedy this gap in understanding, this research offers new insights into 'the whole', and how in/conspicuous detail can be managed by nurses for those that have cardiovascular disease and prediabetes. Knowledge of this nature, concerning complex illness, constitutes intelligent practice that is uniquely nursing.

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## Appendix 1

New Zealand Society for the Study of Diabetes, September 2011

Table 2

### What to do following a screening test for type 2 diabetes

<b>Result</b>	<b>Action</b>	<b>Why</b>
<b>Symptomatic</b>		
<b>HbA1c <math>\geq 50</math> mmol/mol</b> <b>and</b> , if measured, Fasting glucose $\geq 7.0$ mmol/L <b>Or</b> Random blood glucose $\geq 11.1$ mmol/L	No further tests required	Diabetes is confirmed
<b>Asymptomatic</b>		
<b>HbA1c <math>\geq 50</math> mmol/mol</b> <b>and</b> , if measured, Fasting glucose $\geq 7.0$ mmol/L <b>Or</b> Random glucose $\geq 11.1$ mmol/L	Repeat HbA1c or a fasting plasma glucose	Two results above the diagnostic cutoffs, on separate occasions are required for the diagnosis of diabetes
<b>HbA1c 41-49 mmol/mol</b> <b>and</b> , if measured, Fasting glucose 6.1–6.9 mmol/L	Advise on diet and lifestyle modification. Repeat the test after 6-12 months	Results indicate 'pre- diabetes' or impaired fasting glucose*
<b>HbA1c <math>\leq 40</math> mmol/mol</b> <b>and</b> , if measured, Fasting glucose $\leq 6$ mmol/L	Retest at intervals as suggested in cardiovascular risk factor guidelines	This result is normal
* When HbA1c and fasting glucose are discordant with regard to diagnosis of diabetes, repeat testing at an interval of 3-6 months is recommended. The test that is above the diagnostic cut point should be repeated – if the second test remains above the diagnostic threshold then diabetes is confirmed. If the second result is discordant with the first then subsequent repeat testing at intervals of 3-6 months is recommended. Patients with discordant results are likely to have test results near the diagnostic threshold.		

## Appendix 2

### Ethics Approval Letter



26 August 2009

#### Central Regional Ethics Committee

Ministry of Health  
Level 2, 1-3 The Terrace  
PO Box 5013  
Wellington  
Phone: (04) 496 2405  
Fax: (04) 496 2191

Email: [central\\_ethicscommittee@moh.govt.nz](mailto:central_ethicscommittee@moh.govt.nz)

Dr Jeremy Krebs  
Department of Endocrinology  
Capital & Coast District Health Board  
Private bag 7902  
Newtown  
Wellington

Dear Dr Jeremy Krebs

#### **Preventing diabetes in people admitted to the Cardiac Care Unit and hyperglycaemia CEN/09/04/019**

The above study has been given ethical approval by the **Central Regional Ethics Committee**.

#### **Approved Documents:**

- Appendix 3: Health Survey (SF36). 2005, v1.
- Interview schedule: before discharge from CCU. Appendix 1.
- Interview schedule: 9 months after discharge.
- Information Sheet: Reducing incidence of further cardiac events and type 2 diabetes. Version 3, dated 3 August 2009.
- Participant Consent Form. Version 2, dated 3 August 2009
- Advert: Cardiac Rehabilitation Exercise Programmes. Version 3, dated 3 August 2009.
- Transcriber's Confidentiality Agreement. 2005, v1.
- Locality Assessments: Capital PHO, Massey University, GM Primary Care4 Services - Compass Health Wellington, OraToa,

#### **Accreditation**

The Committee involved in the approval of this study is accredited by the Health Research Council and is constituted and operates in accordance with the Operational Standard for Ethics Committees, April 2006.

#### **Progress Reports**

The study is approved until **1 December 2010**. The Committee will review the approved application annually and notify the Principal Investigator if it withdraws approval. It is the Principal Investigator's responsibility to forward a progress report covering all sites prior to ethical review of the project in **26 August 2009**. The report form is available on <http://www.ethicscommittees.health.govt.nz>. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

#### **Requirements for SAE Reporting**

The Principal Investigator will inform the Committee as soon as possible of the following:

- any related study in another country that has stopped due to serious or unexpected adverse events
- withdrawal from the market for any reason
- all serious adverse events occurring during the study in New Zealand which result in the investigator breaking the blinding code at the time of the SAE or which result in hospitalisation or death.
- all serious adverse events occurring during the study worldwide which are considered related to the study medicine. Where there is a data safety monitoring board in place, serious adverse events occurring outside New Zealand may be reported quarterly.

All SAE reports must be signed by the Principal Investigator and include a comment on whether he/she considers there are any ethical issues relating to this study continuing due to this adverse event. It is assumed

by signing the report, the Principal Investigator has undertaken to ensure that all New Zealand investigators are made aware of the event.

**Amendments**

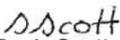
All amendments to the study must be advised to the Committee prior to their implementation, except in the case where immediate implementation is required for reasons of safety. In such cases the Committee must be notified as soon as possible of the change.

**Please quote the above ethics committee reference number in all correspondence.**

The Principal Investigator is responsible for advising any other study sites of approvals and all other correspondence with the Ethics Committee.

**It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. Where applicable, authority for this must be obtained separately from the appropriate manager within the organisation.**

Yours sincerely

  
Sonia Scott  
Central Regional Ethics Committee Administrator  
Email: [sonia\\_scott@moh.govt.nz](mailto:sonia_scott@moh.govt.nz)

## Appendix 3

### Letter of invitation for prospective participants



**Massey University**



**Capital & Coast  
District Health Board**  
ŪPOKO KI TE URU HAUORA

The Diabetes Education  
And Research Centre  
175A Adelaide Road  
Newtown  
Wellington

10 September 2009

To the potential participant

Many people who are admitted to hospital with heart problems can have high blood glucose too. A high percentage of these people who have high blood glucose can go on to develop further heart problems.

Many people are highly motivated to change their lifestyles but don't know how and need some advice as to how to change some part of their life style. There are lots of resources in the community to help but they are often not well utilised.

Dr Harding, one of the cardiology doctors, Dr Krebs, one of the diabetes doctors and a nursing lecturer from Massey University, Kim van Wissen, are running some research to focus on better use of the current resources. They are looking at how people with your combination of health issues, is discharged from the hospital back to the community. In the end it is about better outcomes for patients when they go home.

In this pack we have also included the more detailed information sheet about this study "Reducing incidence of further cardiac events and type 2 diabetes".

If you are interested in knowing more about the research or taking part in this research, please let the nurse on the ward know and they will contact the research team.

Yours sincerely

Dr Jeremy Krebs

Dr Scott Harding

Kim van Wissen

## Appendix 4

### Information Sheet



## INFORMATION SHEET

### Reducing incidence of further cardiac events and type 2 diabetes

You are invited to take part in a study that seeks to reduce cardiac events such as heart attacks and angina, and reduce the development of type 2 diabetes. This study has received ethical approval from the Central Regional Ethics Committee and is being funded by the Health Research Council of New Zealand. The work of a PhD student (Kim van Wissen) is also part of this study.

#### Principal Investigator

**Dr Jeremy Krebs**, Lead Endocrinologist of Endocrine, Diabetes & Research Centre, Capital and Coast District Health Board

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E-mail: [Jeremy.krebs@ccdhb.org.nz](mailto:Jeremy.krebs@ccdhb.org.nz)

#### Co-investigators

Working with Dr Krebs are the research team as follows:

**Cecilia Ross** (Diabetes Nurse Co-ordinator, Endocrine, Diabetes & Research Centre, Wellington Hospital)

Work phone No: 04 806 2458

Emergency No. 027 5458586

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### **Introduction**

You are invited to take part in a study that seeks to reduce cardiac events such as heart attacks and angina, and reduce the development of type 2 diabetes. You have until your discharge from hospital to decide if you would like to participate in the study and have the right to refuse to participate in this study at any time. The above principal investigator or co-investigators can be contacted with any questions you would like answered before deciding to participate.

### **The aims of the study are:**

- To reduce the incidence and/or development of type 2 diabetes and cardiac events for those admitted to Cardiology (Wellington Regional Hospital) with high blood glucose.
- To optimize the primary and secondary health care resources available when you leave Cardiology (Wellington Regional Hospital).

### **How are people selected for this study, and who will select them?**

Patients in Cardiology, Wellington Regional Hospital will be asked by Cardiology staff to be involved in the study if they have a high fasting blood glucose (over 6Mm). If you have a high blood glucose this would mean that you are at-risk of having further cardiac events and possibly developing type 2 diabetes.

### **What will happen during the study?**

The study will take 9 months to complete from the time that you are discharged from Cardiology. You will have usual care throughout your stay in Cardiology. If you are happy to participate in the study you will have additional blood tests taken (checking your lipid profile, glucose, HbA1c). You will also have your weight, height and waist measured, plus blood pressure, and pulse. Most of these measurements are taken routinely in hospital. Before you go home you will be asked to fill out a questionnaire and Kim van Wissen will interview you. Dr Krebs will then randomize you to either the control group (usual follow up in the community) or the intervention group (has a more focussed follow up using services already available in the community and a cardiac rehabilitation exercise programme that you will have to attend). All of this will be organized before you leave the hospital.

### **Timeline for the study**

After you have been assigned to a group (either the control group or the intervention group) your time commitment will be as follows:

***Control Group (usual care on leaving the hospital)***

	0 months (start study) Cardiology	9 months Family doctor	After 9 months Cardiology
Blood pressure	✓	✓	
Heart rate	✓	✓	
Blood lipid profile	✓	✓	
Blood glucose	✓	✓	
Blood HbA1c	✓	✓	
Weight, height, waist	✓		✓
Questionnaire	✓		✓
Interview	✓		✓

***Intervention Group (more organized care on leaving the hospital)***

	0 months (start study) Cardiology	3 months Family doctor	6 months Family doctor	9 months Family doctor	After 9 months Cardiology
Blood pressure	✓	✓	✓	✓	
Heart Rate	✓	✓	✓	✓	
Blood lipid profile	✓	✓	✓	✓	
Blood glucose	✓	✓	✓	✓	
Blood HbA1c	✓	✓	✓	✓	
Weight, height, waist	✓	✓	✓		✓
Questionnaire	✓				✓
Interview	✓				✓

- You will be asked to attend a Cardiac Rehabilitation Exercise programme. We would prefer you attend the programme available at Massey University, Wellington (see page 5). The programme is twelve weeks long, you would need to attend three times a week. You can choose which programme you attend and when you start the programme but it must be done within 9 months
- Visit that includes the questionnaire and interview will be about 2 hours long.
- You will be issued a card to confirm your participation in the research. This card should be presented at the time of any medical treatment received during your participation in the study.

### **Confidentiality**

All data and audio-taped interviews will be kept confidential, securely stored on a password protected laptop or in a locked cabinet in a secure room at the Diabetes Research Centre. Only the researchers will have access to the study data that is collected.

You will not be personally identified in any reports or publications that are developed throughout the course of this research. The data will appear grouped and include no markings that can be traced back to you. The data will be kept for ten years and then destroyed in accordance with current research procedures at Capital & Coast Ltd.

### **Participants Rights**

You do not have to accept this invitation to participate in this research.

If you agree to participate you have the right to:

- Decline to answer any particular question within the questionnaire or during the interview;
- Ask any questions about the study anytime during your participation
- Withdraw from the study at anytime without any affect on your future health care/continuing health care at any time up until the interview transcripts are finalised;
- Provide information on the understanding that your name will not be used unless you give permission to the researcher;
- Be given access to a summary of the study findings when it is completed.

Participation in this study will be stopped should the medical doctor (Principal Investigator of the study) feel it is not in your best interests to continue.

### **What are the potential inconveniences of the study?**

There are no risks in participating in this study. You will have the usual care that is provided by primary health providers on discharge from hospital. There may be an inconvenience for those participants that are in the intervention group travelling to Massey University to begin their exercise programme early in the morning.

### **What are the benefits of this study?**

Participants have the option to carry on with the resources/services that they have accessed. Any findings from this study will contribute to improving the health of all people of New Zealand.

### **Costs for the study**

It will not cost anything to take part in this study, however there may be some costs associated with your usual health care unrelated to participation in this study. Travel costs will not be paid for in this study.

### **Family doctor notification**

Your family doctor will be advised of your participation in the study by letter.

### **Family or Whanau support**

You may have a friend, family or whanau support present at any study visits.

If you have any questions or concerns about your rights as a participant in this research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.

Telephone: (NZ wide) 0800 555 050

Free Fax (NZ wide): 0800 2787 7678 (0800 2

SUPPORT)

Email (NZ wide): [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

### **Results**

A written report of the study will be available to participants on request.

### **Compensation**

In the unlikely event of a physical injury as a result of your participation in this study, you may be covered by ACC under the Injury Prevention, Rehabilitation and Compensation Act. ACC cover is not automatic and your case will need to be assessed by ACC according to the provisions of the 2002 Injury Prevention Rehabilitation and Compensation Act. If your claim is accepted by ACC, you still might not get any compensation. This depends on a number of factors such as whether you are an earner or non-earner. ACC usually provides only partial reimbursement of costs and expenses and there may be no lump sum compensation payable. There is no cover for mental injury unless it is a result of physical injury. If you have ACC cover, generally this will affect your right to sue the investigators.

If you have any questions about ACC, contact your nearest ACC office or the investigator.

**Please feel free to contact the Diabetes Research Centre if you have any questions about this study on 04 806-2458.**

### **Statement of Approval**

This project has been reviewed and approved by the Central Regional Ethics Committee, Wellington Application CEN/09/04/019. If you have any concerns about the ethics of this study, please contact the Chairperson Helen Colebrook on telephone (04) 496-2405 or by email [central\\_ethicscommittee@moh.govt.nz](mailto:central_ethicscommittee@moh.govt.nz)

## **CARDIAC REHABILITATION EXERCISE PROGRAMMES**

Massey University (Wellington) offers prevention, rehabilitation and maintenance exercise programmes to people with cardiovascular disease, cardiovascular risk factors or recovering from a cardiac event. The programmes cover all aspects of exercise to ensure long term recovery.

### **THE PROGRAMMES**

The exercise programmes involve both Phase II and Phase III. Details of the programmes are:

#### **Phase II (monitored clinical programme):**

- Three one hour sessions per week for twelve weeks (7 or 7.30am start; Monday, Wednesday, Friday) for 12 weeks
- Mainly aerobic exercise combined with moderate resistance training with the emphasis on improving functional fitness.
- Exercise intensities, blood pressure and heart rate responses are monitored during the whole programme.
- Fully supervised by qualified staff.
- Exercise prescribed to suit individual preferences and needs.
- Patient's partners welcome
- Report at end of 12 week programme sent to GP
- Option of moving on to on-going maintenance course (Phase III)

#### **Phase III (maintenance programme):**

- Three one hour sessions per week (7 or 7.30am start; Monday, Wednesday, Friday)
- Mainly aerobic exercise combined with moderate resistance training with the emphasis on improving functional fitness.
- Blood pressure and heart rate monitored pre- and post exercise.
- Exercise prescribed to suit individual preferences and needs

### **HOW TO ENROL**

A referral from your medical practitioner or cardiologist is essential for Phase II programme.

For further information regarding the programme and costs, contact the Cardiac Rehabilitation Programme Manager, Jacques Rousseau at Massey University, telephone number (04) 801 2794 extension 6779 or email [j.j.rousseau@massey.ac.nz](mailto:j.j.rousseau@massey.ac.nz)

## Appendix 5

### Consent form for participants



# Participant Consent Form

## Reducing incidence of further cardiac events and type 2 diabetes

This consent form will be held for a period of ten years.

I have read the Information Sheet for this study and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

Please tick the appropriate box

I agree  /do not agree  to complete the questionnaire (SF36 Health Survey).

I agree  /do not agree  to be interviewed.

I agree  /do not agree  to the interview being audio taped.

I want  /do not want  the audio file of the interview returned to me.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: .....

Date:.....

Full printed name of participant

.....

**Diabetes Research**  
175A Adelaide Road, Newtown, New Zealand  
Telephone 04 918-6631, Facsimile 04 385-5948

**Institute of Food, Nutrition and Human Health**  
Massey University, Wellington  
Private Bag 756, Wellington 6140

Consent form, version 2, 3 August 2009

## Appendix 6

**Table: Participants interviewed as per timing and location for interview 1.**

Participant	Sex	Interview 1 Timing of interview
1	M	Withdrawn by GP and never included
2	M	In
3	M	In
4	M	In
5	M	In
6	F	In
7	M	In
8	M	In
9	M	After discharge
10	F	In
11	M	After discharge
12	M	In
13	M	After discharge
14	F	In
15	M	In
16	F	In
17	F	In
18	M	In
19	M	In
20	M	In
21	M	In
22	M	In
23	M	After discharge
24	F	After discharge
25	M	In
26	F	After discharge
27	M	In
28	F	In
30	M	After discharge
31	M	After discharge
32	M	After discharge
33	M	After discharge
34	M	After discharge
Subtotals	F = 8 M = 25	In hosp = 22 After discharge = 11
Total	33	33

Interview 1

In = in hospital in the Cardiac Care Unit before discharge

After discharge = within 2 weeks after discharged home

## Appendix 7

### Schedule for Interview 1

Introduction:

Reiterate the aims of the research

Reiterate the process

Ask the participant if they are happy with proceeding in terms of their participation in the study

Start with:

You have just answered a questionnaire, the SF36, the first question is

In general, would you say your health is: Excellent, Very good, Good, Fair, Poor

**You have answered xxxxx, could you please explain why you marked that particular answer?**

**\*What is the reason why you came to hospital?**

**What is your understanding of why you were admitted to hospital?**

**\*Tell me about how you have been feeling the last week?**

**\*How do you feel about having a diagnosis in terms of a heart condition and then also find out you have a high blood glucose?**

**How does this matter to you?**

Other questions:

\*How are you today?

In general how has your health been the last year?

What have been your main health issues over the last year? Last 5 years?

What is your perception of health right now?

\*How do you see your health will be over the next year?

\*Do you have a heart condition?

\*How likely is it that you will make a full recovery from your heart condition? Explain

\*Can you explain what high blood glucose could mean?

\*What medications do you take?

What are they all for?

Why do you take them?

How long have you been taking medications for?

How do you feel about taking these medications?

\*Do you take OTC medications/drugs?

What are they?

Why do you take them?

\*Do you ever seek out information about your health/illness conditions?

Where/from whom do you get information from about your health issues?

What things do you normally do to keep yourself healthy?

Things to do with diet

Exercise

Regular sleep

Keeping salt to a minimum

Having a regular check-up

Do you discuss your conditions with your family doctor or nurse? Who else?

What sorts of issues do you regularly talk about with them?

Have you got any questions about the health beliefs statements here in front of you?

(select a health belief statement and ask the participant to explain the answer)

e.g. Heart disease is often caused by people's lifestyle is this right or wrong?

## Appendix 8

### Selected questions

#### Interview 1

#### Health beliefs: heart disease & high blood glucose

We want to know your views and beliefs about how and why people get heart disease (angina and heart attack) and have high blood glucose.

Please answer all the statements as either agree or disagree

	Agree	Disagree
You can fully recover from heart disease		
One of the main causes of heart disease is stress		
Heart disease is often caused by a person's lifestyle		
Angina is like a small heart attack		
Once you have one heart attack you are bound to have another		
People who have heart disease should live life to the full		
Having a high blood glucose can mean you have diabetes		
You can fully recover from diabetes		

With permission from Gill Furze, York Angina Beliefs Questionnaire

Furze G, Bull P, Lewin RJ, Thompson DR.(2003). Development of the York Angina Beliefs Questionnaire. Journal of Health Psychology 8(3): 307-315.

## **Appendix 9**

### **Schedule for Interview 2**

#### **Schedule for interview 2**

Fill out SF36

Use SF36 question 1 and ask them to explain their answer in more depth as for interview 1 (experience and understanding)

Ask participant to look at a random statement on the YCBQres and explain why the statement may be right or wrong (understanding)

consider repeating with a new statement, as time allows

#### **Fill out Visit 2 Form**

##### **How have you been over the last nine months?**

(experience and understanding)

Have you been to see your **General Practitioner or Practice Nurse** over the last 9 months?

When?

Why? What reasons?

Are you on Care +

##### **How would you describe the relationship you have with your GP?**

(experience and understanding)

##### **Have you needed to access further health care over the last nine months?**

(any other admissions?)

What sort of health care?

(experience and understanding)

How has your recovery been after your “ACS event”? admission to the hospital where I met you?

What sort of follow up have you had concerning your high blood glucose?

##### **What is your understanding of your illnesses at present? What are the main health issues at present? Why are they the main health issues at present?**

Give the participant an opportunity to ask questions

##### **Discuss OGTT result and any other blood results related**

(understanding)

What sorts of changes have you made to your life(style) since you had XXX 'event'?

Work through list:

**Diet**

**Exercise**

**Smoking cessation**

**Stress**

**Doctors/nurse visits**

**Work life balance etc**

(understanding)

Who has helped you with these changes?

How have the changes you have made to your life benefited you?

(experience and understanding)

**Are you still on the same medications as you were on 9 months ago?**

What are they all for?

(understanding)

**Has your time in hospital 9 months ago changed your life in any way?**

Has it changed your life style

**(How) do you think about the condition of your heart and having high blood glucose together?**

**(How) are they managed together?**

Or are they separate?

(experience and understanding)

What sort of information have you had about your heart condition?

What sort of information have you had about having high blood glucose?

**Show assortment of leaflets as prompts**

**Where and how do you get your health information from?**

(experience and understanding)

What do you think about having this combination of problems?

**What do you think about your illness(es) or conditions?**

What troubles you most about the illnesses and/or conditions that you have?

(understanding and experience)

**Who is your main support person? Do you have a support person?**

**Who really cares about your recovery?**

Who looks after you when you get sick?

When you went home from the hospital, who was your support person then?

**What are your plans for the immediate future?**

Note about questioning:

What do you think . . . ?

What could that mean?

Questions like this to get away from ‘the body’

What are they experiencing . . .

Shift away from medicalisation

Shift away from medical model

Shift to issues that are important to the individual experiencing the juxtaposition of illness(es) and then relate to understanding of their illness.

Appendix 10

Confidentiality Agreement for transcribers



**Massey University**



**Capital & Coast  
District Health Board**  
ŪPOKO KI TE URU HAUORA

**Reducing incidence of further cardiac events and type 2  
diabetes**

**Transcriber's Confidentiality Agreement**

I .....  
(Full name printed) agree to transcribe the recordings provided to me.

I agree to keep confidential all the information provided to me.

I will not make any copies of the transcripts or keep any record of them, other than those required for the study.

Signature: .....

Date:.....

## Appendix 11

### Covering letter for interview (1 and 2) transcript verification by participants



XX August 2011

Dear

**Re: Reducing Incidence of further Cardiac Events and Type 2 Diabetes**

Many thanks for taking part in the study that followed up your risk for developing further problems with your heart and possibly diabetes after you admission to the Cardiac Care Unit in the Wellington Regional Hospital last year. Your discussions and comments made in both interviews with me (Kim van Wissen, research nurse) have been of great value. New points have been made and many other aspects are reconfirmed.

At this point I am verifying all the interviews as they are finally completed. Please take time to read through the written transcripts of your two interviews which are enclosed/attached. You will note that some information has already been removed or altered to safeguard confidentiality and therefore will not read well. It will be important to retain as much of the conversation as possible as this is an important part of the analysis.

If there is any information you wish to have altered or removed from the transcripts please contact me at 801-5799 ext 6755 and leave a message or email me on [K.A.Vanwissen@massey.ac.nz](mailto:K.A.Vanwissen@massey.ac.nz). If I do not hear from you by 12th September 2011 I will assume that the transcripts are in order and you do not wish to make any changes.

I will be in contact again as the analysis progresses later this year. I would like to take this opportunity to thank you for providing us with important information for the study.

Yours sincerely

Kim van Wissen Research Nurse